RESILIENCE IN THE OFFSPRING OF MOTHERS WITH SCHIZOPHRENIA

by

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Abstract

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Eight adult offspring of mothers with schizophrenia were interviewed about their experience of being raised with a mentally-ill mother. Mean age of offspring was 8.6 years when their mothers first displayed symptoms. All offspring were initially from intact married, two parent families. Majority of mothers were mentally healthy, functional parents during participants' early childhoods. Participants experienced ambiguous loss in regard to losing their "pre-illness mother" to schizophrenia. Offspring reported confusion over mother's mental status due to lack of family communication. Offspring children typically felt responsible for somehow causing their mother's illness. Mothers experienced a mean delay of 5.7 years between showing full symptoms and receiving a diagnosis of schizophrenia. Participants noted lack of support from extended family, the community and the mental health system. Offspring described many challenges in getting their emotional needs met and in dealing with stigma from the community. Mother's emotional withdrawal, religious fanaticism, paranoia and delusions were the symptoms most disruptive to family life. Coping strategies of offspring included compartmentalizing home life from their school and social lives with peers, immersing themselves in school and community activities such as sports and using humor. Main sources of support were identified as "my own drive to succeed," "doing things for others," belief in a Higher Power, playing music and relying on fathers, friends and (as adults) spouses/partners. Participants reported experiencing survivor guilt from leaving younger siblings and mother behind when first leaving home. As adults, participants displayed early first marriage (mean =22.2 yrs) compared to general U.S. rates, and decreased mean birth rate of 0.9 children per participant compared to their mothers' mean birth rate of 2.8 children. Participants described not having children as an active choice due to fears that their child or they themselves might later develop schizophrenia (due to genetic risk). For some, being parentified in childhood also contributed to their decision to not have children. The few participants who had their own children considered them an important source of emotional support. Offspring and their families appear to experience the five stages of grief (Kubler-Ross, 1969) in reconciling the loss of mother to mental illness.

Keywords: schizophrenia, offspring of schizophrenic mothers, children of schizophrenics, resilience, stigma, parentification, coping strategies, ambiguous loss, stages of grief, survivor guilt, reflective functioning.

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> *…Then I would see my mother in that dark…apartment, my mother alone with her music, alone with the voices that did not sing… She just hadn't been given a chance to get better…I would be the one to give her that chance… I would rescue my mother and lead her out of the darkness…*
>
> *-Tara Elgin Holley*

Chapter I: Introduction

Much has been written about individuals with schizophrenia, but little about their offspring. The few studies of offspring that have been conducted have focused mainly upon their vulnerability to mental illness, not upon their resilience. These vulnerability studies have generally been long-term, prospective assessments of “high risk” offspring (Goldstein, 1987; Marcus, Hans, Nagler, Auerbach, Mirsky and Aubrey, 1987; Tienari, Sorri, Lahti, Naarala, Wahlberg, Moring, …Wynne, 1987). These researchers consider all offspring of a parent with schizophrenia to be at “high risk” for schizophrenia due to the genes they share with their affected parent. The immediate goal of “high risk” studies is to identify precursors of schizophrenia in the subset of offspring who will go on to develop the disorder. The ultimate goal is to determine the pathway(s) of schizophrenia transmission and the circumstances that promote its expression.

While these are scientifically appropriate and humane goals, they are quite at variance with the goal of this study. “High-risk” literature in general seeks to illustrate the nature of offspring’s vulnerabilities, whether genetic or contextual, and the circumstances that bring these latent vulnerabilities to the surface. Those factors that inhibit the expression of these latencies or get in the way of the circumstances that promote their expression are not of interest in those studies. Here they are my focus.

A resilience study emphasizes the strengths (inner and outer) of the individual and the coping strategies (conscious and unconscious) that he or she employs in resisting the latencies that put him/her at higher risk for mental illness. It also looks at intentionally and unintentionally benign components of context. It seeks not only to recognize the courage, resourcefulness and perhaps good luck of offspring who have healthy outcomes, but seeks to describe how the vulnerabilities with which they begin life are ultimately mitigated, offset and overcome.

In this study, eight American adult offspring of mothers with schizophrenia were interviewed in depth about their childhood and adult life experiences in relation to their mothers' mental illness. The primary goal in choosing this topic was to give voice to the experiences of resilient offspring and to learn from them what is required to overcome the substantial challenge of being the child of a mother with schizophrenia. With childhood developmental courses colored to such a great degree by the shadow of their mother's mental illness, how had these offspring been able to grow into mentally healthy and productive adults? In what ways, for better or worse, did their early experiences with maternal schizophrenia continue to resonate in their adult lives? This proved to be a rich area for inquiry.

A qualitative mode of inquiry was best suited for the complex and idiosyncratic biographical data in which participants could describe their inner thoughts, fantasies and emotional responses to various life experiences. Qualitative instruments have a high tolerance for ambiguities, such as the mixed feelings that one would expect most offspring to have in regard to being raised by a mother with schizophrenia. The qualitative interview I created for the study allowed me to draw a rich and detailed portrait of each offspring. Thus, important nuances in the data were retained.

Qualitative interviewing has been used previously in schizophrenia research. For example, Howard (1998) used this method to study the experience of fathers as caretakers for their adult children with schizophrenia. To date, there have only been two published retrospective, qualitative interview studies of the children of psychotic mothers (Dunn, 1993; Nathiel, 2007). However, Dunn’s (1993) study had a small sample size of nine and not all of the mothers had a diagnosis of schizophrenia. Similarly, while Nathiel (2007) interviewed a larger sample of 18 daughters of mothers with severe mental illness, the majority had mothers with mood disorders and only a subset of six or seven mothers were diagnosed of schizophrenia. Nevertheless, her data on this small subset was valuable and will be touched upon later in the Results chapter.

By interviewing offspring in depth, I hoped to highlight their resourcefulness and resilience. I wished to identify the coping skills they had employed in their childhoods and learn how they had made successful transitions to adulthood. However, in taking a developmental perspective on their resilience, I was not just interested in their end states simply for their own sake, but in how their end states could be extrapolated backwards to the specific resilient capacities that they had employed to answer the challenge of having a mother with schizophrenia. Through post facto comparisons of interviews, I hoped to elucidate common mechanisms of resilience in these offspring.

This study was limited to the offspring of *mothers* with schizophrenia (as opposed to fathers) mainly for pragmatic reasons. Data suggested that, at least in the United States, being raised in a household with a father who has schizophrenia is less common than being raised with an affected mother. Bhatia, Franzos, Wood, Nimgaonkar and Deshpande (2004), comparing individuals with schizophrenia or schizoaffective disorder in the United States (n=144) versus India (n=224) found that males in the U.S. group were more likely to be single and childless than females, and that males with children generally had fewer children than did females. In contrast, procreation rates among Indian males and females with schizophrenia or schizoaffective disorder were about equal. Reasons for this difference between U.S. and Indian samples have not yet been determined.

There are three factors that may reduce procreation rates for males with schizophrenia in the U.S. versus females. First, the age of onset of schizophrenia in the United States is three to four years earlier in males than in females (Torrey, 2001) which may place greater limits on the opportunities of males to procreate. Second, as Torrey (2001) goes on to note:

> Schizophrenia is also a more serious disease in men than it is in women. Men do not respond as well to anti-psychotic drugs, they have a higher relapse rate, and their long-term adjustment – measured by such indices as social life, marriage, work record, suicide rate, and level of function—is not nearly so good as women's. There are, of course, many women with schizophrenia who have had a severe course and men who have done well, but statistics clearly establish that schizophrenia occurs earlier and in a more severe form in the male (p.128).

Third, there is a lingering societal prejudice (frequently promoted by television dramas), that those with mental illnesses, especially males, are more prone to violence than 'normal' adults. Neugeboren (1999) cites "a seventeen-year exhaustive study of television content (that) revealed the fact that 72 percent of characters labeled 'mentally ill' in prime-time dramas were portrayed as violent, and that 22 percent of those labeled as 'mentally ill' killed someone (p.63)." Walsh, Buchanan and Fahy (2002) reviewed the empirical evidence for an association between violence and schizophrenia and found that most studies show a small but significant association. However, they estimated that the percentage of violence in society due to individuals with schizophrenia is small, being less than 10% of all violent crimes. They concluded that co-morbid substance abuse considerably increases the risk of violence and that factoring out crime due to substance abuse would likely decrease rates of violent crime attributed to individuals with schizophrenia.

Despite this empirical evidence to the contrary, the general public is often guided more by their perceptions than by fact. Thus, due to their perception that males with mental illnesses are violent, males with mental illnesses would generally be avoided by women seeking mates. This would again serve to limit males' opportunities to procreate.

For these reasons, I deemed the task of locating a sufficient number of offspring raised with fathers with schizophrenia to be too difficult a task to undertake for this study. Further research is needed to study the offspring of fathers with schizophrenia.

In contrast to males, Torrey (2001) reports that women with schizophrenia are prolific. He writes:

> Since many such individuals (women with schizophrenia) have difficulties in planning ahead…unplanned pregnancies are relatively common among women with schizophrenia: in one study 31 percent of the women had had induced abortions (p. 286) … A study of 80 female chronic psychiatric outpatients' reported that only one-third of the 75 children they had born were being reared by their mothers. Indeed, the loss of child custody by mothers with schizophrenia is very common because many of them are unable to care for the child (p. 287).

While this sounds dire, we should keep in mind that this sample was of women with schizophrenia at the most chronic end of the spectrum. Even so, one-third of them *were* reportedly caring for their children. We should ask, however, what is the quality of that care and what supports are necessary for them to raise their children to healthy outcomes.

Chapter II: Literature Review

There is surprisingly little in the literature about the parenting functioning of mothers with schizophrenia, or about their functioning in family life in general. While there have been several qualitative interview studies on *families* of individuals with schizophrenia, these studies have mainly focused on the care-taking burden of parents who have a child with schizophrenia, (Sakai, Kim, Akiyama and Kurita, 2002; Howard, 1998). In addition, there is virtually nothing in the scholarly literature about being a child growing up in a household with a mother who has schizophrenia. To illustrate this, if one searches the PsychLit database (for the past 20 years) for 'schizophrenia' over 25,000 articles are returned. If one searches 'schizophrenia' and 'offspring' approximately 320 articles are returned, the vast majority of them relating to 'high risk' studies, (i.e. vulnerability studies of offspring). If one searches 'schizophrenics' and 'resilience' (or synonymous terms) 19 articles are returned and only four of these pertain specifically to offspring of a parent with schizophrenia. Of these four, only two, those mentioned earlier by Dunn (1993) and Nathiel (2007), have been prior interview studies of resilience in the offspring of mothers with "psychosis." The present study sought to address this void in the literature.

Research Questions

In writing the interview for this study, I tried to approach it with minimal biases, although this is never completely possible (Mantzoukas, 2004; Harry, 1996; Huberman and Miles, 1985). If the researcher were not curious about particular research questions from the beginning and did not hold particular assumptions (however vaguely formulated), he would not undertake the study in this area. Therefore, I will list some of the global research questions that were in my thoughts during the construction of the interview questionnaire:

1. What is daily life like for the children of mothers with schizophrenia in terms of the pragmatics of life? What changes occur in household as a result of the mother's mental illness?
2. What coping strategies do offspring children successfully employ?
3. What is the process like for the child in coming to understand that their mothers behaviors (i.e. paranoia, delusions) are symptoms of mental illness?
4. Are there discrete stages of 'illness acceptance,' (i.e. coming to terms with the mothers schizophrenia) for the child?
5. Does the child regard the loss of the "healthy" pre-illness mother as permanent or is his/her sense of loss ambiguous in nature?
6. What is the child's internal mental and emotional life like when being cared for by a mother with schizophrenia?
7. Who, if anyone, fulfills the child's unmet emotional needs to be mothered and parented?
8. Is the child able to form a positive self-image, and if so, what supports are necessary for him/her to do so?
9. Can the offspring child imagine himself/herself in the future or is his/her sense of future possibility foreshortened and/or circumscribed (due to a lack of parental modeling and mirroring)?

10. To what degree is the ‘healthy’ father (when there is one in the home) or another relative able to compensate as a parent for the limitations of the mentally ill mother?
11. How, if at all, does the experience of having lived with a mother who has schizophrenia affect the adult offspring’s current ability to form intimate relationships, to work productively and to be a parent to his/her own children?
12. For offspring, does moving ahead with their lives feel like abandoning the ill parent (i.e. do they suffer from some form of survivor guilt)?
13. What similar resilience characteristics and/or resilient strategies are shared by the majority of offspring? What characteristics or strategies are unique to each offspring?
14. Does having siblings mitigate the effects of being raised with a mother who has schizophrenia?

These questions are broad in range, so some were only be touched upon in the study. But, the main focus of the study was upon the first two questions listed: What is life like for children living with mothers who have schizophrenia and how do they cope with the experience?

Demographics

In the following section, I will review the prevalence rates of schizophrenia in the United States, around the world, and according to race. I will also present a brief discussion of how immigration may be a stressor that contributes to developing schizophrenia and how schizophrenia rates may change in a given population through time due to changes in environmental conditions.

Rates of Schizophrenia in the United States

Schizophrenia, a chronic form of mental illness characterized by severe disturbances in the affected individual's ability to think clearly, to interpret reality, to communicate thoughts and feelings and to relate socially with others, occurs in approximately 2.2 million Americans in any given year. Based on the 2000 United States census, of the total U.S. population of approximately 220 million, the number of individuals with schizophrenia is equivalent to 8 persons out of every 1000 (.008%) (Torrey, 2001). Researchers typically round this figure up, using 1% as the estimated risk of developing schizophrenia for a person in the general population with no family history of the disorder. A wide confidence interval would then give a low estimate of 5 per 1000 population and a high estimate of 15 per 1000 in the U.S. population.

Studies indicate that rates of schizophrenia are typically higher in urban areas than in suburban or rural ones. (Lundberg, Cantor-Graee, Rukundo, Ashuba and Ostergen, 2009; Weiser, Van, Reichenberg, Rabinowitz, Nahon, Kravitz, … Davidson, 2007). Thus, if we were looking at *urban* populations in America, we would expect to see rates of schizophrenia somewhat higher than 8 per 1000 and when looking at suburban or rural populations, we would expect to see rates somewhat lower than 8 per 1000.

Until recently, schizophrenia was thought to occur in males and females equally However, new, systematic reviews of epidemiological data from around the world show that males have a significantly higher incidence of schizophrenia compared with females (median male to female risk ratio = 1.4) (McGrath, 2005). According to the "schizophrenia information" website run by the Mayo Clinic (2005): "It (schizophrenia) most commonly occurs between the ages of 13 and 25, and often earlier in males than in females. In men, schizophrenia typically emerges in the teens or twenties. In women, the onset typically is in the twenties or early thirties." The reason for this sex-based difference in age of onset is unknown.

Schizophrenia risk is increased for those who have first-degree relatives with schizophrenia. Current estimates of the risk to children who have one parent with schizophrenia range from approximately 9% to 13% (Andreasen, 2001). Similarly, rates for children with a sibling who has schizophrenia are also about 9%-13% (ibid). If more than one first-degree relative has schizophrenia, rates rise dramatically. For example, if one has a parent *and* a sibling who are affected, one's risk rate is estimated to be 28%-46% (Andreasen, 2001; Torrey, 2001).

The group of 'normal' or 'resilient' offspring of mothers with schizophrenia is the main focus of this study. Given that only 9-13 % of offspring with one affected parent (and no other first-degree relatives with schizophrenia) go on to develop schizophrenia, this means that *the remaining 87% to 91% of offspring with a single affected parent will not develop schizophrenia at any point in their lifetimes.*

That we should have a rate of healthy outcomes of 87%-91% in the direct offspring of mothers with schizophrenia is an astounding fact, considering the cognitive, social and emotional impairments in the mothers of these children, and how these maternal impairments may impact upon their children's development. Even if a subset of these resilient offspring may receive positive parenting from a healthy father or surrogate parent, they still must at some point overcome the effects of having a mother with schizophrenia. These effects may include traumatic separation(s) from their mothers (due to maternal hospitalization or change in parental custody) and the internal psychological issues the child may struggle with in regard to having a mentally ill mother, which may include shame, poor sense of self, poor sense of self-worth, and decreased feelings of self-efficacy.

There are no figures currently available on how many women with schizophrenia living in the United States are mothers. We also do not have figures for the total number of offspring children who have a mother with schizophrenia. Therefore, we must rely on estimates. To estimate the total number of American women with schizophrenia who are mothers, we would have to take the total 2.2 million persons with schizophrenia in the U.S. and using McGrath's (2005) worldwide ratio of 1.4 males to 1 female with schizophrenia, we would get a figure of approximately 917,000 women with schizophrenia.

Howard, Kumar & Thornicroft (2001) found that most women with psychotic disorders (63%) in an epidemiologically representative British population (N=246) were mothers. Similarly, McGrath, Hearle, Jenner, Plant, Drummond & Barkla (1999) surveyed all clients of three Australian mental health agencies and found that 59% of women with psychosis were mothers. These women had fewer children than did their same-sex siblings who did not have mental illness, a result in keeping with prior studies that found rates of procreation to be lower in individuals with psychosis, especially males, than in the general population. Also higher rates of fertility were associated with a later age of receiving a first diagnosis.

For the sake of simplicity, I will take 60% as the approximate average of women with psychosis identified in the two studies who were mothers, and let this figure also stand for the estimate of American women with schizophrenia who are mothers. Taking 60% of the estimated 917,000 total number of women who have schizophrenia in the U.S., yields a figure of approximately 577,000 women with schizophrenia who are mothers.

To estimate the number of children in the U.S. population who have a mother with schizophrenia, we must underestimate the 2.3 average number of children per family that exists in the general population. As McGrath et al (1999) found, mothers with psychosis have fewer children than do mothers in the general population. Again, for simplicity’s sake, let’s use 1.5 as the average number of children for mothers with schizophrenia. Multiplying 1.5 children per mother times the estimated 577,000 mothers with schizophrenia gives a figure of approximately 865,500 children of mothers with schizophrenia in the United States.

World Schizophrenia Rates

One might assume that schizophrenia rates are the same throughout the world, but this is not the case. The United States schizophrenia rate of 8 per 1000 population is comparatively high, almost *twice* the worldwide average. Canada, most European and most Asian nations have prevalence rates in the 3 to 6 per 1000 range (Torrey, 2001). Countries with low measured schizophrenia rates (lower than 2 per 1000) are Ghana, Botswana, Papua New Guinea and Taiwan. Countries (other than the United States) with rates higher than 7 per 1000 population are Ireland, Sweden and Finland (ibid). The highest reported rate comes from a study of people in Northern Sweden whose rate was 17 per 1000, (ibid).

The relatively high rates for the Nordic countries and the low rates for several of the equatorial countries are intriguing. An obvious hypothesis is that the amount of sunlight received throughout the year in these countries may affect rates of schizophrenia development. Hypotheses such as these are important to the present study because they indicate the likelihood that environmental factors play as important a role as do genetics in determining who will and who will not develop schizophrenia.

In planning this proposed study, I assume that environmental variables are crucial factors in determining schizophrenia development. I further assume that offspring of mothers with schizophrenia who remain healthy make use of ‘resilient’ strategies that help them create more favorable environmental conditions for themselves. These may serve to offset their genetic vulnerability to developing schizophrenic illness. I also leave open the possibility that some mothers with schizophrenia are able to maintain parenting functions sufficiently (albeit with periodic interruptions due to illness) to help offset the genetic vulnerabilities in their children and thus raise them to be healthy offspring.

Schizophrenia Rates by Race

On the surface, race appears to play a part in rates of schizophrenia. For example, African-Americans have a schizophrenia rate that is approximately 1.5 times that of Caucasian-Americans (Torrey 2001). However, Torrey argues that because African-Americans live more disproportionately in cities than do Caucasian-Americans that this disparity is more likely due to the effects of urbanism rather than to the effects of race. Studies of rural populations have shown equal schizophrenia rates between African-Americans and Caucasian-Americans (Torrey, 2001). Curiously, Hispanic Americans living in cities have a *lower* rate of schizophrenia than do Caucasian-Americans living in cities. One hypothesis is that the strong social structure of Hispanic families may provide a prophylactic effect upon the development of serious mental disorders such as schizophrenia (Lefley, 1990). We should, however, make a caveat that we cannot judge the strength of the social structure of any given ethnic group based on a single outcome measure such as the incidence rate of schizophrenia in that population. For example, Boyd-Franklin et al. (2003) describe the generally strong social structure of African-American families.

Genetic and Environmental Vulnerability Factors

In this section, there will be a general overview of theories of the etiology of schizophrenia, including a brief review of data from studies on identical twins, neurological findings and new directions for research in the coming decade. There is also a discussion of a selection of “High Risk” or vulnerability studies. Vulnerability factors, both genetic and environmental, such as immigration are discussed that may promote or inhibit the expression of schizophrenia and a brief discussion of life stress as a contributing factor and how the resilient qualities of individuals may offset it.

Etiology of Schizophrenia

Based on current evidence, the cause(s) of schizophrenia appear to be multiple. Most schizophrenia researchers today agree that data supports a genetic component to the disorder. This, they believe, predisposes individuals from families with an affected member to be more likely to develop the disorder than those without an affected family member (Andreasan, 2001). Whether a genetically predisposed individual goes on to develop schizophrenia may depend upon a variety of environmental factors, either singly or in combination. Current hypotheses of schizophrenia causation include purely genetic theories, mixed genetic/environmental theories, theories that it is caused by fetal exposure to viruses (effects of which may remain unseen for twenty years or more) (Torrey 2001), birth trauma to the fetal brain (Guy, J., Majorski, Wallace, and Guy, M., 1983), and social environmental theories such as being raised in a family with a deviant communication style (Goldstein, 1987). There is also a family therapy view that the schizophrenic psychosis of the patient is a symptom manifestation of an active process that involves the entire family (Bowen, 1960).

Hypotheses of schizophrenia causation that have been discredited have been summarized by Torrey (2001). They include the theory that schizophrenia is the result of poor mothering in general (a theory disproved by Prout and White's, (1951) controlled study of 25 mothers of sons with schizophrenia that showed the mothers to be little different from control mothers); that it is the result of having a 'schizophregenic' or 'cold' and domineering mother (Tietze, 1949); or that it is caused by parents who give too many mixed signals emotionally, i.e. Bateson, Jackson, Haley, and Weakland's (1956) famous "double-bind" theory; the theory that poor communication patterns in the family of origin cause schizophrenia (Lidz, T., 1992), and finally, the theory that schizophrenia is a fiction "invented" by psychiatrists to keep themselves in business, the illness "being a sane response to an insane world (Szasz, 1976)."

Studies of Identical Twins

If schizophrenia developed solely from genetic causes, one would expect a high concordance rate for the disease between identical twins (as they share identical genetic material with each other). However, the concordance rate for schizophrenia for identical twins is only approximately 30% (Andreasen, 2001). This is an important fact for the present study because offspring children may share many genetic similarities with their mothers. However, this low concordance rate indicates that genetic similarities are not of themselves reliably predictive of whether a given offspring will go to develop schizophrenia. Similarly, Sullivan, Kendler, and Neale (2003) conducted a meta-analysis of 12 twin studies and found they “are consistent with a view that schizophrenia as a complex trait that results from genetic and environmental etiological influences. (p.1192).”

Neurological Findings: A Brain Based Disorder

A number of studies have supported the viral theory of schizophrenia that it is initially triggered by exposure to a virus during fetal development in the womb. Torrey (2001) reports that the finding has been replicated several times that approximately 10-15% more births of individuals with schizophrenia occur during the winter and spring months (December-April), after time periods where mothers were prone to be exposed to viruses. He asserts that, following several decades of debate, schizophrenia has been proven to be a brain-based disorder:

> Over 100 MRI studies have shown that the cerebral ventricles, which carry cerebrospinal fluid throughout the brain, are on average 15 percent larger in individuals with schizophrenia. An additional 50 studies have been done on structures of the limbic system using MRI and neuropathological evaluation of postmortem brain tissue; these studies have shown volume loss, cell loss and changes in the architecture of the cells in the hippocampus, amygdala, parahippocampal gyrus, entorhinal cortex, and cingulate. In most studies, the differences between individuals with schizophrenia and normal controls is subtle, in the range of 5-10 percent and there is some overlap between individuals in the two groups. What this means on the practical level is that the brain changes are not specifically diagnostic for schizophrenia, that is, they cannot be used by themselves to say that a person has or does not have the disease (pp.144-145).

This is important to the present study as it suggests that children of mothers with schizophrenia may share some similarities in brain architecture with their mothers, but these do not necessarily indicate a propensity toward future development of schizophrenia.

Many studies have demonstrated various neuro-cognitive deficits in those who have schizophrenia. For example, Broerse, Crawford and Den Boer (2001) present an overview on a main focus of this research, the study of saccadic eye movements. These are eye movements that control the ability to track objects in the visual field smoothly . 'High risk' studies of offspring have sought to identify irregularities in saccadic eye movements in offspring as showing a predisposition to schizophrenia (Mather, 1985). However, no correlation between displaying this irregularity and the development of schizophrenia has been proven.

New Directions: The Human Genome and Epigenetic Theory

Up to now, genetic researchers have hoped to identify the gene(s) responsible for causing schizophrenia on the chromosomes of human DNA. However, after considerable effort no single gene has been reliably identified. As a result, many researchers no longer expect to discover a single gene, but rather hope that a constellation of multiple genes that collectively contribute to the development of schizophrenia will be found. Meanwhile, with the human genome now fully mapped, a potential paradigm shift is currently occurring in schizophrenia research (Andreasen, 2001). A new wave of researchers have discovered "epigenetic" material--that is, genetic material that exists in human cells outside of the DNA-- that may determine which genes on the strands of DNA will be switched on or switched off. These epigenetic switches may soon prove to be a key factor in determining whether the genes for schizophrenia will be “turned on” or “turned off” for a given individual. These epigenetic findings may also have an impact in the coming decade upon the search for the genetic underpinnings of many other diseases.

‘High Risk’ Studies

‘High risk’ researchers have shown considerable interest in the degree to which the offspring of individuals with schizophrenia share neuro-cognitive similarities with their affected parent. Several ‘high risk’ studies have detected neuro-cognitive deficits or “soft signs” in a minority of the offspring of parents with schizophrenia. These include the difficulty with saccadic eye movements (Mather, 1985), trouble with perceptual sensitivity in vigilance tasks (Nuechterlein, 1983) and conceptual disorganization in spatial tasks (D’Angelo, 1993). Researchers, such as those in the St. Louis High Risk Project, have also shown decreases in I.Q. scores and I.Q stability in the children of mothers with schizophrenia from approximately age eight to age sixteen (Worland, Weeks, Weiner & Schectman, 1982).

A problem in the majority of such studies is that the healthy offspring of mothers with schizophrenia are aggregated into the same grouping with the minority of offspring who will go on to develop schizophrenia. This results in the inadvertent masking of normal and sometimes high I.Q. scores of many offspring children. Also, the presence of these deficits have *not* been reliably predictive of which individuals will later develop schizophrenia.

In the NIMH Israeli Kibbutz-City Study, Marcus et al. (1987) looked at Israeli offspring who had a parent with schizophrenia. One aspect of their study was to compare kibbutz-raised children versus city-raised children. Interestingly, they found higher rates of schizophrenia development in the offspring who had been raised on the kibbutz. (This finding ran counter to the conventional observation that rates of schizophrenia are higher in urban areas than in rural areas). The authors hypothesized that children raised on the kibbutz, due to the tight-knit social community there, could not escape the awareness of others that they were children of a mentally ill parent and therefore were forced to contend with the effects of social stigma. In contrast, children raised in the city could possibly keep private this aspect of their family history (and thus could to a greater degree avoid social stigma). An implication of Marcus et al's finding is that a genetically vulnerable individual's experience of social stigma may have an impact upon whether that individual will develop schizophrenia. However, I hypothesize for the proposed study that individual characteristics of resilience in offspring of mothers with schizophrenia may mitigate the negative effects of experienced social stigma.

In addition to their finding of higher rates of schizophrenia in kibbutz-raised offspring of schizophrenics, Marcus et al. al. looked for multiple factors in the development of schizophrenia. First, they attempted to account for genetics, by comparing children of parents with schizophrenia (n=50) versus controls (n=50). Second, they reviewed individual birth and early childhood histories to compare individuals with neurobiological deficits versus those who had none. Third, they considered family environmental causes, by comparing the parenting behavior of the couples with a schizophrenic member versus control parents. Fourth, they measured the social adjustment of each child as seen by parents and teachers. Using a decision-tree model, they found that no cases of adult schizophrenia appeared on the control group side of the tree. In contrast, 9 total cases of adult schizophrenia were seen in the offspring of a parent with schizophrenia. The largest concentration of cases, seven, were seen on the far side of the tree where all four factors were present: 1) child of a schizophrenic, 2) neurobehavioral deficits in infancy, 3) receiving poor parenting and 4) showing poor social adjustment. In addition to these seven cases, there was one positive case where the affected individual had *not* been rated as having poor childhood adjustment, and one case where the child had *not* been rated as having been parented poorly, but all other factors for both had been positive.

Similar results were seen in the Jerusalem Infant Development Study (Marcus, J., Hans, S.L., Nagler, S., Auerbach, J.G., Mirsky, A.F. and Aubrey, A., 1987) where a similar group of children at 'high risk' for schizophrenia were followed from infancy to middle childhood. A subgroup of children showed sensory-motor dysfunction in the first year of life, which was followed by perceptual, motor and attentional dysfunction in childhood—identical to that found in the NIMH study cohort. Results from both studies support the hypothesis that schizophrenic illness involves constitutional factors whose expression can be seen by trained observers as early as infancy.

Stress as a Contributing Factor in the Onset and Course of Schizophrenia

Life stress has been identified as a prime environmental factor that affects onset or influences the course of many diseases, such as peptic ulcer (Levenstein, 2000) and multiple sclerosis (Steck and Steck, 1998). In both these diseases, stress is seen as influencing the immune system through modification of the hypothalamic-pituitary-adrenal axis, a key player in the body's stress response. Similarly, researchers do not see life stress as causing schizophrenia, but feel it may accelerate the onset of disease and affect relapse rates (Torrey, 2001). High levels of stress have been hypothesized to trigger the initial onset of schizophrenic symptoms, as well as subsequent episodes where there is a temporary worsening of symptoms. The disease course for schizophrenia is variegated with affected individuals going through periods where symptoms are sometimes better, sometimes worse (ibid).

In conjunction with the disease course of the individual, the family of the individual with schizophrenia also goes through a variegated course of stress in relation to the ill person's state. Sakai Y., Kim, Y., Akiyama, T., & Kurita, H. (2002), in studying a Japanese sample found that individuals with schizophrenia often have a "low awareness" of their own schizophrenia. They found first that the individual's "low awareness" significantly contributes to the mental "ill-health" of other family members; and second, that "the burden on families for care of the schizophrenic (person) (is often) so high that the families could not clearly recognize the schizophrenic (person's) symptoms and did not consider those symptoms as a psychotic state (p.1091)."

Sakai et al.'s (2002) observation that family members widen their boundaries for what they see as acceptable behavior suggests a key phenomenon that may occur in families that have a member with schizophrenia. In widening the boundaries of what they view as 'normal' behavior, family members may be responding to an unconscious habituation response or they may be doing so consciously in order to allow the behavior of the individual with schizophrenia to be viewed as more acceptable. This phenomenon may be more indicative of an accommodation process within the family rather than what may sometimes be seen as the family's 'denial' of the person's illness. As in many other human interactions, when people make accommodations to each other, stress levels are naturally decreased.

The children of mothers with schizophrenia may thus use this kind of mental accommodation to their parent’s illness as one mechanism of resilience. However, certain individuals may be more or less aware of their own widening of the boundaries of what they see as acceptable communication and other behavior. Thus, offspring children may benefit from the accommodation process when dealing within the family, but may discover that when dealing with others outside the family that their style and/or range of communication and other behavior may be viewed as unusual or even strange. Offspring’s individual characteristics of resiliency may then come into play in determining whether they feel good, bad or indifferent about communicating and/or behaving in a manner that may differ in some ways from the norms of society.

Immigration as a Risk Factor

Several studies have looked at immigration as a risk factor in the development of schizophrenia. For example Iverson & Morken (2003) examined psychiatric admissions (n=3,053) to a Norwegian hospital among immigrants, asylum seekers and Norwegian-born patients. Analyzing the cases of all immigrants (94) and asylum-seekers (39) versus a control sample of Norwegian-born patients (133), they found that admission rates were the same for immigrants and Norwegians, although somewhat higher for asylum-seekers. However, there were differences in prevalence of diagnoses given at discharge within each group. Diagnoses of schizophrenia were more frequent in women of the immigrant group. The authors suggest that the stress of immigration may cause more cases of schizophrenia than in those who are native born and that women in the immigrant group are more likely to develop schizophrenic psychosis than men. They speculate that the impact of immigration may be more severe upon women because women may rely more on their familiar social network and this is often lost through immigration.

In contrast to the results of this study, Cochrane & Bal (1987) argued against an association between immigration and schizophrenia. They tried to account for the higher rates of schizophrenia found among Irish, Indian, Pakastani and Caribbean immigrants living in England in 1981. The exception was that Pakastani women had conspicuously low rates of admission for schizophrenia. The authors, argued that the higher rates of schizophrenia admission in Indian men and women and Pakastani men were due to demographic differences, and that the higher rates for Irish-born immigrants were comparable to the higher rates found in Ireland. They suggested that the lower rates for Pakastani women is likely due to their being reluctant to seek psychiatric services. Nevertheless, they were unable to account for the marked, higher rates of schizophrenia among Caribbean-born immigrants.

Resilience

The term “resilience,” as noted by Radke-Yarrow & Brown (1993) comes out of the Materials Sciences where it is defined as “the ability of a material to resume its original shape or position after being spent, stretched or compressed (p.8)” (quoted in Goldstein & Brooks, 2005). The study of resilience as a construct in psychosocial research is just over 30 years old and has only in the past decade begun to blossom more fully.

The study of resilience in children grew as a counterbalance to the high-risk, vulnerability studies on children of schizophrenics that were prominent in the 1960’s and 1970’s. Martin and Powell (2003) describe this area of research as beginning with the work of Garmezy (1974) on Project Competence at the University of Minnesota. Garmezy had previously been involved in high-risk research and was struck by the high numbers of offspring of schizophrenic parents who were not just doing okay in life, but who were excelling. His observation led to a growing notion in the field that these children had exceptional individual characteristics. They were described as "psychologically invulnerable," (Anthony, 1974) or as "superkids" (Kauffman, Grunebaum, Kohler & Gamer, 1979). Following this, there was a shift in the field to a more dynamic stance where researchers such as Rutter (1987b) were looking, "for the developmental and situational mechanisms involved in protective processes (p.2) ," (quoted in Goldstein & Brooks, 2003, p.3). Rutter (1987a) described further that, "The resilience these children display is conceived as an end-product of buffering processes that do not eliminate risks and stress in their lives, but that allow the individual to deal with them effectively," (quoted in Werner, 2005).

Masten, Best and Garmazy (1990) define resilience as "…the process of, capacity for or outcome of successful adaptation despite challenging or threatening circumstances." They found that children who overcome chronic adversity "fare better or recover more successfully when they have a positive relationship with a competent adult, are good learners and problem solvers, are engaging to other people, and have areas of competence and perceived efficacy valued by self and society (p. 441)."

Counselors who help at-risk children typically suggest these types of interventions in helping children avoid negative life outcomes. They try to get children involved in programs and activities such as sports and performing arts that cause them to become involved with a competent adult such as a coach, dance teacher or theatre director.

Counselors also try to help children maintain strong school performance so that they can feel effective in the school environment, even if they are experiencing stress and disorganization at home. While these types of interventions make sense to most people, there may be other factors that are as important or more important in helping children become resilient to adversity. I hope this proposed study will yield this data.

Social Aspects of Schizophrenia

In this section I will discuss social aspects of schizophrenia, most notably stigma, both for the mother with the disorder and her children, and then I will compare society's response to schizophrenia with its response to two other disorders: Parkinson's disease and Aquired Immune Deficiency Syndrome(AIDS). Following this is a section hypothesizing that differences will be seen in the experience of participants in the proposed study who are the children of treated versus untreated mothers, a section presenting data suggesting that mothers with schizophrenia may retain some ability to parent and a discussion of attachment between mothers with schizophrenia and their children.

Schizophrenia: A Stigmatized Disease

The offspring of mothers with schizophrenia can be viewed as dealing with two major issues which while overlapping are really separate issues: first, the actual effects of the mother's illness upon the mother-child relationship and second, the effects of stigma that the offspring face when relating to the wider social community in regard to their mother's illness. Due to social biases that continue to exist today, schizophrenia is one of the most strongly stigmatized diseases.

Unlike Parkinson’s disease, a neuro-cognitive disorder that is discussed freely in the media by celebrities affected by it (i.e. Katherine Hepburn, Michael J. Fox), the family members of individuals with schizophrenia, fearing stigma, have for the most part learned to keep discussions regarding schizophrenia under wraps. They wish to keep this problem within the family, a situation somewhat similar to when people first became aware of AIDS (Acquired Immune Deficiency Syndrome). In that case, however, as the public’s knowledge of AIDS increased, and perhaps more importantly, as people saw that people with AIDS who took appropriate medication could live successfully with the disease for many years, stigma regarding the disease gradually decreased (Link and Phelan, 2001).

Remarkably, a similar public education process is yet to occur in regard to schizophrenia, a mental disorder that has likely been with us since biblical times and which was were first formally defined (and referred to as “dementia praecox”) by Emil Kraepelin (1897) and Eugen Bleuler (1911). The child whose mother has a socially-acceptable, but dangerously deadly disease like AIDS or cancer likely has a more positive set of expectations regarding society’s response to him/her than does the child whose mother has a stigmatized disease such as schizophrenia. The apparent reason for this disparity is because serious psychological symptoms are the defining characteristic of schizophrenia. In addition, society at large still tends to blame the victim in regard to schizophrenia, preferring the notion that the disease is caused by some kind of character flaw in the individual rather than facing the fear that this disease could happen to anyone. (N.B. Similar notions were rampant at the beginning of the AIDS crisis when many people expressed the belief that everyone with AIDS had gotten the disease by their own choice, either through being promiscuous or through abusing intravenous drugs).

A hope of this study is that by generating a picture of mothers with schizophrenia (and their children) that is humane and multi-faceted, that this may contribute to a decrease in social stigma regarding those who have this particular form of disease.

Mothers with schizophrenia may retain some ability to parent

Until the past few years, there has been little in the literature regarding the parenting abilities of mothers with schizophrenia. Bosanac, Buist and Burrows (2005) completed a meta-analysis of existing literature on the subject and found the research severely hampered by methodological constraints. These included a paucity of prospective studies that recruit mothers with schizophrenia before they give birth, problems with changes in the psychological classification of the mothers, the heterogeneity of postpartum psychotic disorders (with the majority of mothers being classified with mood disorders, rather than schizophrenia), selection biases and pragmatic difficulties inherent in studying mother-infant dyads during inpatient stays and, the difficulties of retrospective studies in general, with the specific problems inherent in interviewing women experiencing psychosis.

Despite these difficulties, a few researchers have focused on the parenting issues of mothers with schizophrenia. Goodman (1987) studied the parenting styles of mothers with schizophrenia, mothers with depression and normal controls with children from birth to age five. Both mothers with depression and schizophrenia were rated as less affectively involved with their children than well mothers. Mothers with schizophrenia were rated as providing the poorest environment overall, i.e. less play stimulation, fewer learning experiences and less emotional and verbal involvement. Possible protective factors in mothers were less severity of illness, older age, higher level of education, higher I.Q., work experience and the presence of a spouse/partner or other adult in the home to help with childcare.

Similarly, Abel, Webb, Salmon, Wan and Appleby (2005) compared the parenting abilities of mothers with schizophrenia (N=239) and mothers with affective disorder (N=693) who had been referred for treatment. They found that mothers with schizophrenia were characterized as having more complex clinical and psychosocial problems and were considerably more likely to experience all types of parenting problems compared to mothers with affective disorder. The mothers with schizophrenia who had supportive marital and other relationships, healthy spouses and higher socioeconomic status showed better parenting outcomes than mothers with schizophrenia who did not have these supports. The authors concluded that successful parenting is related partly to stability within the family and access to social and financial resources.

In contrast to these studies, there is a small body of evidence in the literature that suggests that being raised with a mother who has schizophrenia may not necessarily be a harmful experience. For example, Seeman (2010) studied mothers with schizophrenia, and while noting there are potential risks for offspring, found that “Most of these appear to be mediated not by the illness itself but by associated risks: poverty, substance abuse, domestic violence, social isolation, and/or substandard housing(p.55).” She concluded that, “Schizophrenia poses problems for offspring but does not preclude effective parenting (p.56).”

Higgins, Gore, Gutkind, Mednick, Parnas, Schulsinger and Cannon (1997) found that being reared by a mother with schizophrenia does *not* increase one's own vulnerability to developing schizophrenia. They conducted a 25-year follow-up of 50 children of mothers with schizophrenia. The mean age of the children at the time of the original interview was 14.6 years. Twenty-five of the children were reared with their mothers and twenty-five were reared apart from them. Results of the follow-up interview showed a slightly higher incidence of psychosis in the 'reared apart' group. Higgins suggested that the children of the 'reared apart' group could not be reared with their mothers because their mothers' symptoms were possibly more severe than those of the mothers in the 'reared with' group. He felt that this might indicate that the children of the 'reared apart' group had a genetic predisposition to a more severe form of the disorder. (It should be noted, however, that there was no direct evidence of this). Higgins et al.'s results are, however, valuable to this proposed study because they indicate that lifetime diagnoses do not provide evidence that being reared with a mother who has schizophrenia increases the vulnerability of the offspring to schizophrenia. Another possible implication of these results is that children who are permanently separated during childhood from their biological mothers may be at greater psychological risk for developing psychosis than are children who remain with their biological mothers, even if those mothers are struggling with schizophrenia.

The present study looked at whether mothers with schizophrenia can retain some ability to parent their children, and if so to determine the quality of this parenting and the quality of attachment between the mother and her children. I could find nothing in the current literature that speaks to the parenting ability of mothers with schizophrenia. This void is suprising considering the fact that this is precisely the kind of information that family courts would need when deciding whether to allow a parent with schizophrenia to retain custody of their children.

Attachment between mothers with schizophrenia and their offspring

Naslund, Perssin-Blennow, McNeil, Kaij and Malmquist-Larsson (1984) studied infant attachment at one year in 46 offspring of mothers with “non-organic psychosis,” versus 80 demographically similar control offspring in the natural environment of their homes using a modified version of the “strange situation” (Ainsworth and Wittig, 1969; Ainsworth & Bell, 1970; Ainsworth, Blehar, Waters & Wall, 1978). Using the three attachment types representing “secure attachment” (Type B), “anxiously avoidant attachment” (Type A) and “anxiously ambivalent attachment” (Type C), they found a 30% higher rate of “anxiously ambivalent attachment” (Type C) in the offspring of a parent with schizophrenia group. However, this type of attachment is typically viewed as more secure than the “anxiously avoidant” category (Type A).

If one is looking at the proverbial water glass as half full, this study indicates that a small percentage of mothers with schizophrenia are capable of nurturing secure attachment in their infants. Another larger percentage of mothers, while not being able to nurture the secure Type B attachment in their relationships with their infants, are also not creating more “anxiously avoidant “ type infants, the category with the worst prognosis. While their bond with their infant may be characterized as “anxious” and/or “ambivalent,” they are still achieving a bond with their infant that may provide them with “good enough mothering,” to borrow Winnicott’s (1962) phrase. The implication for the present study is that one source of resilience or the offspring of mothers with schizophrenia may be “good enough mothering” or in some cases even “secure,” early attachment to their mothers. Certainly, secure attachment would be possible in offspring whose mothers were mentally healthy from their births through their early childhood period and who did not develop schizophrenia until a number of years after the offspring were born.

Longitudinal studies of attachment have shown that infants who are rated as securely attached fare better in many ways in later childhood, adolescence and adult life than infants rated as insecurely attached. For example, Main (1983) studied 40 mother-infant dyads and found that infants who were securely attached at 12 months of age were more competent at 21 months of age in exploratory behavior, social behavior, cognitive development and language. Cohn (1990) assessed 89 six-year-olds and found them to be perceived as less aggressive and to be better liked by peers, and rated by teachers as being more competent and having fewer behavior problems. Simpson (1990) found in a study of 144 adult dating couples that secure attachment was associated with greater relationship interdependence, commitment, trust and satisfaction with their partners.

While attachment status appears to be stable across the lifespan for the majority of individuals, attachment status is dynamic and does change for some. Waters et al. (2000) conducted a twenty-year, longitudinal study of attachment in 60 white, middle-class infants at 12 months of age (retaining 50 at twenty-year follow-up). As adults, 72% received the same attachment classification that they had received as 12-month-old infants. 36% (18 of 50) of the total participants reported negative life events (defined as loss of a parent, parental divorce, life-threatening illness of parent or child, parental psychiatric disorder, and/or physical or sexual abuse by a family member), and of these

44% (8 of 18) changed attachment classification. Of the 64% (32 of 50) that reported no negative life events, only 22% (7 of 32) changed attachment classification.

While, the majority of individuals in this study who changed attachment type as adults, changed in a negative direction, from secure to insecure, it is also possible that individuals could change in the positive direction from insecure attachment to secure. This could result from positive changes in life experience such as entering a supportive marital relationship or having children. The proposed study will interview participants in depth about life changing experiences that may have resulted in positive changes in attachment type.

Offspring's Experience of Mothers with Schizophrenia

In this section I will discuss in detail the published memoir of a woman who is the daughter of a mother with schizophrenia. Following this is a general discussion of the pragmatics of family life for offspring and how their mothers' impaired functioning may result in role confusion within the family. There is also a discussion of offspring children experiencing the loss of their mothers as ambiguous in nature, which may complicate their grieving process. The section concludes by looking at the availability and appropriateness of support services for offspring children.

Published Memoirs

There have been several published memoirs of individuals who have had schizophrenia, i.e The Quiet Room (Schiller & Bennett, 1994); Welcome Silence (North, 1987), and those who have been parents, i.e. Tell Me I'm Here (Deveson, 1992) or siblings, i.e. Mad House (Simon, 1997) of individuals with schizophrenia. These have been popular rather than scholarly. To my knowledge, there has only been one published account of a child of a mother with schizophrenia, a wonderfully detailed account entitled *My Mother's Keeper: A Daughter's Memoir of Growing up in the Shadow of Schizophrenia* by Tara Elgin Holley with Joe Holley (1997). In this book, Tara Holley describes how her mother, Dawn Elgin, a promising, Hollywood jazz singer in the late 1940's developed schizophrenia shortly after Tara's birth. Dawn (and Tara's) odyssey with the illness takes them from Hollywood to New York and then to back to Dawn's original hometown of Houston, Texas to live with their extended family. After Dawn's years of difficulty with treatment compliance, and Tara's attempts as a young adult to get her mother into a community residence, Dawn eventually becomes a street person in Austin, near the University of Texas campus where Tara is enrolled as a university student. Tara struggles to keep the fact secret from her friends and professors that one of the street people living adjacent to the campus is her mother. While disavowing her mother publicly, behind the scenes Tara makes spirited efforts to save her.

Tara Holley's book touches upon many of the themes that I would expect to hear from participants in the proposed study. First, she describes the child's constant wish for a normal family: "I would imagine what it was like to be a little girl in a normal family, with a mommy and daddy, brothers and sisters." She presents her enduring optimistic wish that her mother with schizophrenia would simply get better. Holley writes, "But if (my mother) could sing, if she could still make music, didn't that prove that she could get better?" She describes frequent fantasies of rescue: "I would rescue my mother and lead her out of the darkness that kept her confused and off-balance." And, due to high levels of social stigma regarding the illness, overshadowing all aspects of Tara's childhood is her pervasive sense of shame regarding her mother's illness and her fear that talking about it to others would betray her mother. She writes in a simple prose that strikes me as Joycean in its style:

> Mentally ill. It was like a confession. It was as if I had confessed the most horrible of sins. The words themselves were horrible. I was betraying my mother, telling an awful truth to the world.

Holley also describes her panic as a child of being found out: “Uh-oh, they (classmates) know. They know. Somehow they know that my mother’s crazy...” She describes taking great pains to keep the secret even from her best friend:

> Though we were the best of friends, I had never told Hallie about my mother. She just wouldn’t understand—or maybe she would have, but I would have hated her pity as much as her scorn… I was so ashamed.

Tara goes on to describe her need to constantly put out great effort to keep her school life completely separate from her secret home life: “ I could keep my strangeness compartmentalized, but I had to work hard at it. Neither Hallie nor any of my friends ever came to my house.”

Tara describes her internal ache of not being emotionally nurtured by her mother: “From her, I needed assurance and acceptance. These were gifts, of course, she was unable to offer.” She alludes to her mother’s inability to provide the normal parental mirroring function for her childhood development:

> I wanted a mother (and father) that I could watch and know and love. I also wanted a glimpse of future possibility, a sense of who I would be in a few years when I was grown and on my own. To imagine my mother as my future was more than I could bear…

This last line introduces another theme that I would expect many participants in the proposed study to present: the struggle with a pervasive terror that they too would eventually become mentally ill like their mothers. How would this fear impact upon the child's ideas about him/herself and his ability to plan for his/her future? Given Tara Holley's description of feeling at a loss due to lacking a model of an adult version of herself, how was she able as a child and adolescent to imagine her future? How did she plan for a life and career (she eventually becomes a musicologist) when she took it as a given fact that she would not make it to adulthood with her mind intact?

Pragmatics of Family Life: Household Disorganization and Role Confusion

The offspring of mothers with schizophrenia face every day challenges that their peers typically do not. In non-affected families, one or both parents provide an organizing influence upon the household and the children. They clean and repair the house, buy groceries and clothing and organize the family's social life. They help their children develop self-organizational skills by modeling them and by nurturing the children through the gradual process of becoming self-organized (i.e.reminding children to do their homework and other tasks). Parents adjust their assistance with these tasks based on the age and level of need of each child.

This parental organizing influence, usually taken for granted in non-affected families, typically does not exist in the household of the child whose mother has schizophrenia. Beardslee and Podorefsky (1988) found that "an important theme in (the) accounts (of children of parents with serious affective or other psychiatric disorders) was the sick parent's unavailability to perform usual tasks, as well as their own considerable initial anger and frustration about not knowing what was going on (p.66)." In their homes, everyday household tasks such as cleaning, doing laundry and food shopping may only be done haphazardly, if at all.

Non-affected parents also typically structure time for their children, making meals and bedtimes at set times so that their children can develop a sense of structure and predictability to their day, giving the children a general feeling of safety and control over their environment. In the household with a mother who has schizophrenia, meals and bedtimes often occur at variable times. Children may have no reminders about homework, permission slips for school or anything else. As a result, these children may have more difficulty in sensing a structure to their lives and internalizing a feeling of safety and self-efficacy. In time, many of these children may learn to precociously meet their own needs, i.e. doing their own laundry, completing homework without reminders, even buying their own clothing and/or cooking their own food. But, although they may more or less manage, they likely will not internalize the same set of feelings about the reliability of their caretakers and the predictability of their world.

Ronald Seifer (2003), a professor of psychiatry at Brown University, explains this difference further in writing about families that contain a parent with any form of affective illness. He writes:

> In families where one or both parents have psychopathology, the jobs of daily life don’t get accomplished smoothly; family members don’t communicate with each other as well as in homes without illness; goals aren’t defined as well, they don’t problem solve as well, and the family as a unit doesn’t seem to work as well… These children don’t have the models for organizing their lives that children whose families function better are going to have. They may not develop organizational skills in terms of interacting with their social peers, solving complex problems, engaging in things that require long-term plans and organization, such as writing a book report.

How an offspring child reacts to and defends against this household disorganization may depend upon the individual. Some offspring may become hyper-organized while others may become lackadaisical to a fault and begin to identify with the feeling of disorganization as normal. After this is internalized, they may later feel uncomfortable in jobs and relationships that would provide them with a sense of structure and stability.

Seifer (2003) is interested in developing preventative models of treatment for children who are at risk for psychological disorders (i.e. the children of parents with affective illnesses). He writes that protective factors that may decrease the risk for these children are:

> Knowledge that their parent(s) is ill and that they are not to blame; help and support from family members; a stable home environment; psychotherapy for the child and the parent(s); a sense of being loved by the ill parent; a naturally stable and happy personality in the child; positive self-esteem; inner strength and good coping skills in the child; a strong relationship with a healthy adult; friendships, positive peer relationships, interest and success at school; healthy interests outside the home for the child; help from outside the family to improve the family environment (e.g. marital psychotherapy or parenting classes).

While participants in the present study were surveyed on their utilization of these protective factors, the semi-structured format of the qualitative interview was crucial in drawing out details of the balancing act that offspring children must perform in their daily coping. Having a mother with schizophrenia in the home is like having a proverbial elephant in the living room. In many aspects the child’s life may proceed as normal, especially when the child is in the company of caring adults and peers such as at school. But each time the child returns home, he/she must somehow get his/her mind and spirit around the problem in the living room.

Holley’s (1997) description of her pervasive sense of shame in regard to her mother’s schizophrenia seems informative here. While offspring children may function well at school and even excel at academics and extracurricular activities, we still must consider their internal emotional life and attend to it. It seemed unlikely at the outset of this study that any offspring child could successfully cope with a problem as large as maternal schizophrenia without some external support such as psychotherapy, or at least a trusted adult in whom they could confide. So, participants were surveyed on their sources of support and their childhood (and adult) usage of therapy services. This data will be discussed in the Results chapter.

Ambiguous Loss

The offspring of mothers with schizophrenia who have experienced the mentally healthy, pre-illness version of their mother, must deal with the loss of her. This loss, however, is and will continue to be ambiguous in nature. The child can see that mommy is physically there, but can also perceive that she is no longer emotionally present. This must be confusing to the child because the mother has not died, but the emotionally present mother that he/she knew is no longer there.

Family therapist, Pauline Boss (1999) in her book, *Ambiguous Loss*, describes how emotional paralysis can grip the children and spouses of those who are ambiguously lost in families. Her writing stems from her experience working with the families of soldiers who have gone missing in action. She later elaborated her work to include family members of those who are “lost” to mental illness, brain injury or Alzheimer’s disease. She writes:

> Perceiving loved ones as present when they are physically gone, or perceiving them as gone when they are physically present, can make people feel helpless and thus more prone to depression, anxiety, and relationship conflicts. How does ambiguous loss do this? First, because the loss is confusing, people are baffled and immobilized. They don’t know how to make sense of the situation. They can’t problem-solve because they do not yet know whether the problem (the loss) is final or temporary. If the uncertainty continues, families often respond with absolutes, either acting as if the person is completely gone, or denying that anything has changed. Neither is satisfactory. Second, the uncertainty prevents people from adjusting to the ambiguity of their loss by reorganizing the roles and

> rules of their relationship with the loved one, so that the couple or family relationship freezes in place. If they have not already closed out the person who is missing physically or psychologically, they hang on to the hope that things will return to the way they used to be (pp.7-8).

One would expect that an offspring who experiences the ongoing ambiguous loss of his mother to schizophrenia, would generate powerful and enduring fantasies about the return of the mentally-healthy pre-illness version of his mother. (This would be similar to the children of divorce who almost universally generate powerful fantasies that their parents will reunite). Considering Holley's (1997) autobiographical account, the child does not necessarily need to have experienced the pre-illness mother to create these fantasies. In her memoir, young Tara spends most of her childhood (and adulthood as well), hoping for the magical return of her mother as a healthy, aware, and nurturing parent. She had developed this fantasy despite the fact that her mother had been ill since immediately after her birth. Having never experienced the healthy version of her mother, she had to construct this image based on information she gleaned from other relatives.

Boss (1999) also talks about the importance of rituals, both familial and societal, in moving families toward resolutions of emotional challenges such as the death of a loved one. However, she explains that these rituals are not available to those suffering from ambiguous loss:

> …Third, people are denied the symbolic rituals that ordinarily support a clear loss—such as a funeral after a death in the family. Few if any supportive rituals exist for people experiencing ambiguous loss. Their experience remains unverified by the community around them, so that there is little validation of what they are experiencing and feeling. Fourth, the absurdity of ambiguous loss reminds people that life is not always rational and just; consequently, those who witness it tend to withdraw rather than give neighborly support, as they would do in the case of a death in the family. Finally, because ambiguous loss is a loss that goes on and on, those who experience it tell me that they become physically and emotionally exhausted from the relentless uncertainty (p.8).

> …People can’t start grieving because the situation is indeterminate. It feels like a loss, but it is not *really* one. The confusion freezes the grieving process. People plummet from hope to hopelessness and back again… (pp.10-11).

From the internal confusion that may occur inside the child and other family members, Boss goes on to discuss effects on the family system as a whole. She writes:

> …Family members can become so preoccupied with the loss that they withdraw from one another. *The family becomes a system with nobody in it* (italics mine). This scenario, of course, plays out in varying degrees of severity, depending upon the family and the nature of the loss (p.11).

The present study looked at the grief process and adaptations of families to the ambiguous experience of losing the mother to schizophrenia. I italicized the sentence about the family system having no one in it, because several participants made reference to the loneliness of family life following the onset of the mothers’ mental illness. I would try to keep in mind, however, that all family situations are dynamic. While participants described a strong tendency to fragmentation within their family systems, these were still, in many cases, intact families with certain strengths. They all had the potential for resilience and healing even though the grief process may have become stalled due to the ambiguous nature of the maternal loss. This will be discussed further in the Results chapter.

Lack of Focused Psychological Treatment for Offspring

To my knowledge (having been a special education teacher and counselor in schools for over a decade), there is currently no screening done in American schools to identify children who have a parent with schizophrenia or any other major mental illness Often indirect evidence of a parent having a mental illness may be suggested to a teacher, counselor or social worker (i.e. a child may inadvertently make a reference to the parent being ‘abnormal,’ or a child’s parent may never attend any required school meetings, or the parent may have a disheveled appearance or odd manner), but even when teachers and school counselors suspect parental mental illness, they are typically at a loss as to how to address the issue. Providing treatment for the parent or even giving them a referral is generally beyond the scope of their position. If they provide individual therapy to the child it is likely to be supportive, not a therapy that specifically addresses the issue of parental mental illness. Thus in the course of the therapy, the issue of parental mental illness may typically be compartmentalized while therapists focus on the everyday school experience of the child and their peer relationships. While such therapy may be useful to the child, it may also inadvertently reinforce the child’s assumption that their parent’s mental illness is shameful and should remain secret. Due to subtle (and sometimes not so subtle) communications such as this from these trusted adults, and also due to the child’s ongoing experiences of social stigma regarding parental schizophrenia from society at large, I would hypothesize that the vast majority of children who have a parent with schizophrenia, even as adults, would be highly reluctant to seek therapy in any form. The present study looked at offspring’s patterns of therapy seeking and they will be discussed in the Results.

Cowling, Luk, Mileshkin, and Birleson (2004) surveyed the children of parents with severe mental illness (referred by the parents’ case workers) in Australia. They found 25% of the children in the clinical range on the Strengths and Difficulties questionnaire (SDQ), meaning they experienced a level of life difficulty that urgently required counseling. They recommended that a good time to perform such brief mental health screenings on the children of the mentally ill is at the time when their affected parent is first brought to a mental health center for treatment. In my opinion, doing so would be beneficial as it would promote the idea that maternal schizophrenia is a major problem for the whole family that requires counseling interventions and social supports for each family member. This position is also advocated by Wasow (1995) who states, “The ripple effect of mental illness on the entire family is enormous (p.3).”

The proposed study will survey participants on their use of counseling and psychological services, as children and as adults, in order to get an idea of patterns of use for the children of mothers with schizophrenia. It will also look at what obstacles may be in the way of offspring children seeking help.

Chapter III: Methods

The qualitative method of interviewing employed in this study was developed by Glaser and Strauss (1968) and is known as “Grounded Theory.” This method is described fully in Charmaz (2006).

The first eight of nine adult offspring of mothers with schizophrenia spectrum disorders who referred themselves for the study were chosen to complete the interview. (One was eliminated as her mother did not have schizophrenia) The protocol consisted of a 25-item written, demographic survey[1] that took participants 15-20 minutes to complete, followed by a 34-item oral interview[2] that took approximately three to three and a half hours. In addition to the 34 set questions, the interviewer asked follow-up questions in order to delve further into areas of particular interest with each participant.

Interviews were audiotaped with participants’ permission. After the first interview was transcribed in full, it was decided that time would be used more efficiently if only the nine most pertinent questions were transcribed and coded in the manner prescribed from grounded theory. The remaining interviews were then transcribed in this abbreviated manner. These transcripts were then coded by creating a verbal label, or substantive code, that captured the meaning of each phrase of raw data. Substantive codes chosen were in plain, non-theoretical English and stayed as close as possible to the expressed meaning of the interviewee. At the same time, the substantive codes were one level of conceptual abstraction above the raw data. This movement to one level of abstraction above the raw

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[1] Written by Michael McLoughlin, M.A.

[2] Written by Michael McLoughlin, M.A.

data allowed subsequent statements by the same participant, or similar statements by subsequent participants to be assigned the same code.

Once all phrases were assigned substantive codes, these codes were analyzed and found to cluster into five major areas. These five areas became the foundation of the descriptive theory produced by this study. By building the analysis from the ground up in this way, the likelihood was increased that all categories generated came directly from the actual statements of participants. From this analysis, I was able to generate theory as to what are some of the essential common features of being a child growing up with a mother who has schizophrenia.

In addition to detailed grounded theory coding of responses to these nine questions, themes that emerged from the material from other questions were discerned using the less micro-analytic, more global approaches of psychobiographical research (Newton, 1995). In this approach, rather than coding sentence by sentence, as in grounded theory coding, the researcher abstracts themes from the larger meaning units (approximately a paragraph in length).

One of the benefits of using a qualitative interview approach was that the uniqueness of each participant’s story was retained. This uniqueness was crucial in showing the great variety of situations and events that offspring experienced. The semi-structured design of the questionnaire allowed the interviewer the freedom to pursue unique aspects of each participant’s story.

In order to retain this rich data, following the transcription, coding and analysis of all eight interviews, the life stories of three participants that were representative of the heterogeneity of the group were selected and written into mini-biographies of those participants. (All names and identifying facts were changed to protect participants' confidentiality). These appear in Appendix C. This primary source data presents with more continuity and detail the wide ranging experience of the children of mothers with schizophrenia.

Participant Selection

The eight participants chosen for interview were all self-referred. Three responded to recruitment flyers posted on physical bulletin boards at the outpatient center of the Western Psychiatric Institute and Clinic in Pittsburgh (WPIC). Two were recruited through flyers posted at Allegheny Children's Initiative in Pittsburgh, a community mental health provider. Two were recruited through a local Internet bulletin board in Pittsburgh that is viewed by the general public and one was recruited by word of mouth.

All participants were initially interviewed in person, although two participants completed the final hour of their interview over the phone on a different day following their initial face-to-face meeting. Participants were paid $40 for the two to three hour interview.

Sample Bias

Due to the locations where flyers were posted, individuals who work in the mental health field may be over-represented. It was initially expected that participants would be recruited from support groups for family members of individuals with schizophrenia (and to come from a wide range of occupations). However, none of the participants belonged to such a group. Instead, three providers of mental health services, one person attending group therapy at WPIC and one graduate student in English literature responded to the posted flyers. Two others, a graduate student in social work and a paralegal, responded to the internet posting.

All participants were employed with the exception of one who had worked as a nurse for many years before retiring on disability. This study may also have a bias toward the more motivated and perhaps emotionally healthier end of the spectrum of adult children of mothers with schizophrenia. This bias, however, should not affect the validity of this study as it is qualitative in design and does not seek to be representative of all children of mothers with schizophrenia. Selecting participants from the more motivated end of the spectrum will likely aid the study's primary objective of illustrating the resilience of this group. Further research will be needed to access less motivated and less well-functioning offspring of mothers with schizophrenia.

Criteria for Participant Inclusion

Criteria for inclusion were to be an adult between the ages of 21 and 65 who was raised in the same household with his/her biological mother who had schizophrenia, to be free of 'major mental illness' (defined as never having been diagnosed with any form of psychosis, schizophrenia, or bipolar disorder), and to have demonstrated at least 'minimal life success' (defined as maintaining full-time employment, full-time college or graduate school enrollment, or full time childcare duties for at least the two years immediately prior to the interview). Being "raised in the same household with a biological mother who had schizophrenia' was defined as having lived in the same household with their mother for at least ten years (time period did not need to be continuous as maternal hospitalizations were expected to have been periodic disruptions). Each participant was required to affirm that a qualified medical doctor had diagnosed his or her mother with schizophrenia or a schizophrenia spectrum disorder. Due to the inherent difficulty in obtaining the medical records of a third party, participants’ verbal report was accepted for their mothers’ diagnoses. However, the participant’s description of the mother’s symptoms also had to meet DSM-IV-TR criteria for a schizophrenia spectrum disorder in the opinion of the interviewer, in order to be included in the study

Potential for Interview Questionnaire to be Generalized

This interview questionnaire may be generalized for use with offspring of parents with mental disorders other than schizophrenia, such as bipolar disorder or depression. However, further research is needed to determine if it would be useful with those populations.

Chapter IV: Results

Interviews were transcribed and the nine most pertinent questions were chosen for coding using the grounded theory procedures described in the Methods chapter. These questions (including some of the probe questions within each question) were:

4) What is your earliest memory of your mother?

8) About how old was your mother when she first displayed noticeable symptoms of mental illness and how old were you at that time? How much did you understand at the time about what was happening and what were your feelings about it?

18) As a child how did you feel about sharing information about your mother with others? Did you ever feel that you had to keep your mother's illness a secret and what did you imagine would happen if this secret was revealed to others? As an adult have you told others about your mother's illness and if so with whom and how did you feel about sharing this with them?

20) Who and/or what were your sources of support during your childhood in the time period(s) when your mother was ill? Who and or what kept you going?

22) What was it like when you first moved away from home, i.e. to attend college or to live in your own place? Was separating from your mother and family easy or difficult or a combination of both and why?

23) What have romantic relationships been like for you? What aspects of relationships are easy or hard? What effect if any has your mother's illness had on your ability to enter into and sustain love relationships?

27) At times when life feels difficult, describe what sustains you, i.e. a relationship(s), religious beliefs, a philosophy, an attitude, etc. or what combination of things?

28) Describe the personal qualities in you that have allowed you to overcome the difficult circumstances of having a mother with schizophrenia? What are the sources of your resilience?

33) If you met a child today who was living with his/her mother who had schizophrenia, what advice would you give to him or to her?

These questions generated 182 open codes. These individual codes were then grouped into categories. Individual codes listed under their respective categories appear in Appendix B.

In addition to detailed grounded theory coding of responses to these nine questions, themes that emerged from the material from other questions were discerned using the less micro-analytic, more global approaches of psychobiographical research (Newton, 1995). In this approach, rather than coding sentence by sentence, as in grounded theory coding, the researcher abstracts themes from the larger meaning units (approximately a paragraph in length).

In addition, to being interviewed, participants filled out a brief written questionnaire in which they rated their sources of support, results of which appear in Table 1 below. The questionnaire also included demographic information that supplemented responses to the interview. Specifically, this information allowed construction of a coherent narrative of the sequence of events and experiences starting with the earliest memories of their mother and other data reflecting their memories of their "pre-illness mother," and bridging that period with the one explored in the answer to Question 20 ("Who and/or what were your sources of support during your childhood in the time period(s) when your mother was ill?"). Thus, even though the answers to the questionnaire were not coded in the same grounded theory manner as the data emerging from the interview, they are valuable and are integrated into the presentation of the results.

Together, the material derived from grounded theory analysis, more global psychobiographic analysis and the written questionnaire data led to the identification of five broad domains of participants' experience of their mother's schizophrenic illness:

1. The Pre-Illness Mother
2. Dealing with Mother's Active Illness
3. Dealing with the Community: Secrecy versus Disclosure
4. Launching: Separating from Mother
5. Lasting Effects: Impact of Mother's Schizophrenia on the Adult Lives of Offspring.

Each of these areas will be explicated in a summary narrative that weaves together information from each of the eight participants. The stories of three representative participants were also written into mini-biographies and are presented in Appendix C for those readers who want to read their stories in more continuity and detail.

The results will be presented as follows. First, sample characteristics of participants and their mothers with schizophrenia will be described. Next, will be a discussion of each of the five domains of participants' experience presented with the codes derived from the interview data. Integrated into this section will be examples of the more global psychobiographic data and responses to the questionnaire on sources of support.

Sample Characteristics

The first eight of nine persons who offered to participate were included in the study. One person was excluded because her mother did not have a schizophrenia spectrum disorder. Three participants were recruited from flyers posted at a psychiatric institute, two from an internet posting, and three by word of mouth. No men responded to the flyer or to the internet advertisement, even after multiple postings. (The one man in the study was recruited by word of mouth). That far fewer men responded to the opportunity to participate in this study may indicate that men, in general, are less willing or less able than women to process the experience of being raised by a mother with schizophrenia.[3] In any case, although the present sample is small and not meant to be representative of all adult children of mothers with schizophrenia, it is particularly limited in terms of capturing the experience of men.

Participants ranged in age from 24 to 56 with a mean age of 38.6 years and a standard deviation of 9.4 years. Six participants were born and raised in the United States and two were born in the United Kingdom and became naturalized U.S. citizens as adults. Six of the eight mothers of participants were also born and raised in the U.S. One mother has always resided in the United Kingdom and one was born and raised in Italy and immigrated to the United Kingdom as a young adult. All of the offspring participants were native speakers of English.

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[3] Although it is well established that women volunteer for psychological studies at higher rates than men do as shown, for example, in the work of Martin and Marcuse (cited in Rosenthal, 1965).

Participants' highest levels of academic achievement were: one with a Ph.D., three with bachelor's degrees and some graduate school, three with bachelor's degrees and one with an associate's degree. Three individuals were single/never married, two were currently married and three were divorced (one was divorced twice and another was remarried and then separated). Of the five participants who had married, the mean age at the time they first married was 22.2 years with a standard deviation of 2.8 years and a range of ages 19 to 25. Four of the eight participants had a current spouse or partner and those relationships had a mean duration of 14.5 years with a standard deviation of 13.6 years and a range of between 1 and 36 years. The marriages of the three participants who subsequently divorced had a mean duration of 8.3 years with a standard deviation of 1.3 years and a range of 7 to 11 years. Participants' own children will be discussed in the Adult Functioning of Offspring section below.

Four of the eight participants had current full-time employment, two were pursuing graduate degrees and working part-time, one was pursuing an associate's degree in a new field after having obtained a bachelors degree, and one was retired on medical disability. Participants' occupations were: preschool teacher/ behavioral therapist with children, registered nurse (retired on medical disability), Ph.D. child psychologist, master's level psychotherapist/ researcher, theatre set builder/ performance artist, part-time paralegal/ business student at a community college and two graduate students--one in English literature and one in social work. Specific data on socio-economic status was not obtained, but all participants stated that they considered themselves to be middle-class.

All eight of the participants' mothers were married before they had children. The mean duration of all eight marriages was 21.9 years with a standard deviation of 18.4 years and a range of 6 to 51 years. Five mothers had marriages ending in divorce or separation and the mean duration of these marriages was 9.2 years with a standard deviation of 4.3 years and a range of between 6 and 16 years. Three mothers have had long-term marriages that are ongoing (at the time of their child's interview) with a mean of 43 years, a standard deviation of 8.8 years and a range of between 34 and 51 years at the time of interview.

The age of the mothers when they gave birth to their first child ranged from 18 to 33 years with a mean of 25.4 years and a standard deviation of 4.7 years. One of the mothers had five children, four had three children, two had two children and one had one child. This yielded a total of 22 children born of the eight mothers with schizophrenia, or a birth rate of 2.8 children per mother. Of the eight mothers, only one had developed schizophrenia prior to giving birth to her first child. The birth order rank of the offspring children participating in the study were five oldest, two youngest and one only child.

Five of the eight participants have mothers who are still living. Three of these five mothers are still married and living with their husbands and two are divorced and live alone with some outside supports. Of the three mothers who are deceased, none of their deaths was the result of suicide. (One of the other mothers had attempted suicide unsuccessfully). Two mothers died of breast cancer and one from congestive heart failure. In all three deaths, the mothers' general distrust of doctors and delays in seeking medical treatment were major contributing factors in their deaths.

The three deceased mothers’ last marital status was two who were divorced and one who was separated long-term. The last living situation of the three deceased mothers was one living alone with outside supports, one living with the participant’s maternal grandmother and one living with her child (the participant in the study).

The Pre-Illness Mother

Earliest memory of mother. Each participant was asked to describe their earliest memory of their mother in order to get a general impression of the quality of their early attachment to her. For the purposes of this study, the term “attachment” is used in its’ broad meaning of “emotional connection” to mother. The study simply looked at whether this connection was positive or ambivalent. All but one of the participants’ mothers developed schizophrenia at least several years after the participants were born. Therefore, all but one could remember their pre-illness mother.

Three participants expressed a positive earliest memory of their mother. Codes for these (Table 2) included: *being able to explore/ pursue goals, being able to rely on and trust mother, being comfortable being alone, early mother being loving /caring/ expressing affection, feeling safe with mother* and *feeling a positive bond with early mother.* One participant, Steve, for example, described an idyllic family afternoon in which he was able to play/explore alone and to feel the protection of both his parents:

> (I’m) playing with toys at (my parents’) feet, like Legos or something like that…I’m aware of her presence. It’s just a total family scene. They’re reading and I’m playing. You know, it’s quite peaceful. I’m engrossed in the toys, but I guess I’m feeling their protection over me. All my memories of my childhood of my mother are that she was very loving and very motherly in every way… (She was) a parent who loved being a parent. And then looking at photographs of us in our childhood days, you can see her eyes are lit up with our presence. It’s like she’s sort of glowing as a mother…

Another participant, Karen's earliest memory reflects her feeling safe with her mother (as well as showing Karen's adeptness at using humor to cope with feelings of sadness):

> Oh, I'm probably five or six and I remember this smell (small laugh with pleased tone). I remember my mom in the kitchen…of our home wearing one of those unfortunate kinds of muumuus, you know, a housecoat type of thing, but she had the most delicious smell. She smelled like flowers. And I just remember feeling really safe (voice begins to catch) with her (begins to cry) um, and having her feel like a mom, like she was caring and… (crying)… I think that's probably the earliest and, you know, just tucking me in and just being that warm being, I think, yeah. Ahhhh (collecting herself), I'm already crying and we're only on question four, come on (laughs)!

In contrast, five participants had ambivalent early memories of their mothers. Codes for these (Table 3) included: *ambivalent feelings toward mother, feeling alone, feeling anxious about separating from mother, feeling pushed away by mother, not feeling a bond with mother, feeling the need to be around people/ uncomfortable being alone, feeling shy and insecure as a child, mother treating child as an extension of herself* and *feeling that mother wasn't there for me /can't trust mother*. For example, Laura's earliest memory reflects her feeling that her early mother was pre-occupied and not there for her:

> …I see mom in the rocking chair and I'm kind of playing in the middle of the living room floor and my sister is born too, but she is not even walking…It's very separate. Everybody's very separate. Mom is watching (my sister) very closely. I'm just sort of off by myself. Not really by myself, (but) nobody is really interacting with anybody…My mom is paying close attention to my sister making sure she doesn't get hurt. And (my) feeling I guess around that would be, I don't know, like attention-seeking, like I want some attention.

Carol's earliest memory shows her uncertainty as to whether her mother's presence was loving and protective or not:

> … When I was about two, I remember being on the cot...and she was standing over me, just looking in the cot…and my dad was angry. We were in their

> bedroom and … they had been arguing, I guess, because I could hear the yelling and stuff, and she had come over. I don't know if I was crying or not, I can't remember. But I do remember her looking down. I was just kind of lying down and…I don't know if she was checking on me to see if I was o.k. or not… (and I'm feeling) not too good, scared, fear, I guess…It's just strange, I never felt a bond with my mother. I don't know why. I just never felt there was a bond there. And it was almost like a disconnect. I would never call them 'mom' and 'dad.' Even to this day I cannot make myself do it.

Participants' earliest memories, whether positive or ambivalent, suggest that their mothers, prior to illness, were active participants in the care of their children and the lives of their families. They also reflect significant variation between participants in the emotional quality of presence and care that their mothers provided them.

The remaining headings and subheadings represent qualitative codes illustrated by passages from interviews. Table 2 presents the codes.

Pre-illness mothers are functional adults and parents. In seven of the eight cases, participants (as far as they were able to discern as children) viewed their mothers prior to illness as typical mothers. Analysis of responses to question 5, "Tell me what your mother was like prior to her illness," showed that their mothers were generally loving, affectionate, able to have fun, devoted to caring for them and their siblings, engaged with their husbands, involved with friends and able to pursue interests of their own. Steve whose mother did not become mentally ill until he was sixteen had the benefit of a longer view of her functioning prior to illness than did other participants. He said confidently, "I think my mother was a good parent before she was mentally ill." Carol described that she often had fun with her mother despite her parents' chronic marital conflict:

> Before she was ill…it was quite a rocky home I grew up in (due to my parents arguing), but we did have good times. We had times when we laughed and… we played games and we listened to music and just did stupid stuff and had a good

> laugh. And my relationship was okay with my mom, it wasn't … (trails off expressing sadness).

The majority of the participants' mothers were homemakers whose daily functions included caring for their children and husbands, doing the shopping, planning and making meals, cleaning the house, doing the laundry, helping the children with their homework and taking them to and from school and to sports and community activities. In the one case where the participant's mother was not able to function in the maternal role prior to schizophrenia, this was due to her being impaired by abusing alcohol daily.

Some of the pre-illness mothers were able to teach their children to be goal-oriented. For example, two participants recalled how strongly their pre-illness mothers continually stressed the importance of doing well in school and working hard. Even post-onset, these two mothers were able to continue advocating for their children's education in periods when they were lucid. Both participants give the main credit to their mothers for laying the foundation for their later academic success.

Responses to question 6, "Tell me about your mother's talents and achievements prior to illness," indicated that most of the mothers had held jobs prior to getting married and having children but then stopped working after they had started raising their families. Two of the mothers were later able to return to working full-time following divorce. The participants' mothers had held occupations that included bank teller, store counter person, hair stylist, Sunday school teacher, keyboard/organ instructor, clothing buyer for a department store and the director of a preschool. All but one of the mothers had completed high school and three went on to complete college degrees- one in social work, one in education and one in biology (graduating at the top of her class).

Dealing with Mothers Active Illness

Setting events / possible environmental contributing factors. Data in this section is taken from analysis of questions 5, 6 and 7 (What was family life like before your mother became ill?). Several participants identified significant separations from family and familiar social networks as possible environmental setting events for their mothers' subsequent development of schizophrenia. A number of participants described that their mothers' symptoms began or were exacerbated following a family move to a new geographic location.

Donna described that her mother had hemorrhaged as a newborn and nearly died. Although she had no known illness, she developed an identity growing up, promoted by Donna's grandmother, that she was a weak and sickly child. Donna's grandmother was constantly sending her mother to lie down and rest after the slightest exertion. When Donna's mother married and moved away to the suburbs, this was the first time she had been on her own without her mother to help her regulate herself. Donna believes this was traumatic for her and that it set the stage for her mother to develop psychological symptoms. She believes that her mother's symptoms of schizophrenia were triggered by a post-partum depression she experienced following the birth of her second child, Donna's brother.

Robin's parents had moved to Florida right after they had married, away from family and friends in the New York area. Her mother had been fine for the first decade there, but when her husband resumed doing night shifts as a police officer, she became intensely angry at him for leaving her alone in the house at night, as she had always been scared of being alone. Marital conflict became chronic and her parents divorced when she was nine. Robin thinks the divorce somehow triggered the onset of her mother’s symptoms although it took some time for her psychosis to fully develop.

Karen described that her mother had been particularly close with Karen’s maternal grandfather, but he died when her mother was a senior in high school. This was a traumatic loss for her and Karen believes her mother never fully recovered from it. She thinks her mother was still depressed when she went away to college the next fall. She eventually managed to get through college quite well, graduating third in her class with a degree in biology. She married Karen’s father right after graduation and had Karen’s brother and Karen. The family moved around frequently due to her father’s job transfers. Karen thinks that all of these family moves reawakened in her mother the depressive feelings of her first move away to college right after the death of her father. Karen also believes that her mother’s loss of social connections through the moves were difficult for her. At the first childhood home that Karen remembers, her mother was surrounded by friends, but when they moved to a suburb of Chicago, her mother lost this support network. She became depressed and socially withdrawn and showed an increased religiosity by going to church every day. After a subsequent move to the Pittsburgh area her mother became fanatically religious and began displaying symptoms of psychosis (that will be described more fully later in this chapter).

Carol reported that her family moved frequently from town to town in the north of England due to her father’s attempts to escape paying back rent to their landlords. Her mother’s behavior had always been somewhat erratic and aggressive due to her family of origin being what Carol described as “a bad bunch” with a reputation for fighting in the community and holding nothing back. Sexual abuse by brothers and cousins was endemic in their family and when Carol was an adult, her sisters confided that they and her mother had all been abused as children over long periods of time. Carol feels this definitely contributed to the background of her mother's schizophrenia. Carol described that her mother became more unpredictable, aggressive and hyper-religious after a family move away from her family of origin when Carol was about eight.

In the case of Steve, while his mother had immigrated to a new country as an adult, the genetic factors of her schizophrenia seem to take precedence. Steve's mother and her twin sister had been young girls in Nazi-occupied Italy during World War II. As their father was involved in the resistance, there was a need for the utmost secrecy in the home. She and her sister would be severely reprimanded if they ever spoke to anyone outside the family. Steve feels that this early childhood experience later colored his mother's schizophrenia in terms of her suspiciousness and hyper-vigilance. She and her twin sister had parallel lives, moving together to a coastal city in Italy together at age sixteen to run a shop. There, they each met and married a successful, upper-middle class man when they were about age twenty. She and Steve's father, a doctor, moved to London shortly after they married and his mother assimilated to the English manner and way of life completely. They settled down and had Steve and his two younger sisters. For a number of years, it was a happy family (see Steve's earliest memory in the section above), but when Steve was nine or ten his parents started fighting, mainly about the amount of time his father spent out of the home due to his medical practice. When Steve was eleven, they divorced and his mother had difficulty with the separation. Despite receiving alimony and child support, she needed to go back to work. She tried to get a job as a pre-school teacher while going to college for a degree in social work. Steve feels this was a very stressful period for her as she was trying to raise three children alone, while going to school and looking for work at the same time. After graduating, she opened a progressive pre-school and became its director. She seemed to be over the divorce and doing well. However, when she was thirty-seven and Steve was sixteen, she suddenly became depressed, withdrawn and paranoid that she was being watched. She had stopped eating for the most part and when she went to the hospital received a diagnosis of schizophrenia. Steve subsequently learned that his mother’s twin sister, who had similarly divorced several years earlier, had also had a breakdown within months of his mother and had also been diagnosed with schizophrenia.

Development of schizophrenia in mothers. Data from the written questionnaire (taken with responses to interview question 8) showed that the mean age when mothers first displayed symptoms of mental illness that the participants were aware of was 33.9 years with a standard deviation of 5.2 years and a range of 26-43 years. The mean age of the children when their mothers first displayed symptoms was 8.6 years with a standard deviation of 4.0 years and a range of 3-16 years for the seven participants whose mothers developed schizophrenia after their birth. (Not included in these numbers is the one participant whose mother developed schizophrenia two years prior to her birth).

All of the offspring saw negative symptoms of schizophrenia in their mothers such as excessive sleeping, expressing flat and/or inappropriate affect, being withdrawn, being inattentive, and being emotionally unavailable. Most also saw positive symptoms in their mothers including excessive agitation, paranoia, hyper-religiosity, delusions and responding to visual and auditory hallucinations. A subset of three mothers showed aggression to objects and to people post-illness, but this was not universal. Only two of the eight participants reported ever being physically abused (hitting) by their mothers. There were no reports of sexual abuse by mothers with schizophrenia.

Participants were asked how their fathers responded to their mother's illness and how, it at all they, discussed it with them (interview question 11). Seven participants reported that they had never had any discussions in childhood with their fathers or any other adult family members to help them understand the dramatic changes taking place in their mother's behavior. Their fathers maintained their denial that their mother's illness, sometimes for years. Thus, not only were offspring typically in a state of confusion as to what was happening to their mothers, they felt that that their father's denial undermined their perception of the situation. The father's denial may reflect that they were in the initial stage of the five stages of grief (Kubler-Ross, 1969) in regard to the "loss" of the mother. This theme will be explored in the Discussion.

Learning that something is "not right" with mother. Codes for '"learning that something is "not right" with mother appear in Table 4 (taken from interview question 8: How old was your mother when she first displayed noticeable symptoms of mental illness and how old were you? How much did you understand at the time about what was happening and what were your feelings about it?). Codes consisted of: *Anxiety/worry, anger at God (for making mother ill/for not curing mother), anger at mother (for not being emotionally available),* b*ecoming hyper-vigilant to mother's moods, blaming father (for not getting mother help), feeling confused by changes in mother*, *feeling depressed /withdrawn, feeling lack of information (re: what's wrong with mother), feeling powerless (to help mother), feeling responsible for causing mother's illness /doing* *penance, feeling that something is "not right" with mother, nightmares/ changes in sleep, walking on eggshells (around mother).*

Six of the eight participants were between the ages of three and ten when their mothers first displayed noticeable signs of mental illness, and as young children are not versed in recognizing mental illness as such, participants were confused and realized only that something was "not right" with their mother. They often stayed in this state of uncertainty for many years. Carol describes how she couldn't grasp what was happening when her mother first started showing signs of mental illness when she was 23 years old and Carol was five:

> I didn't have a clue. I didn't understand mental illness. I'd never had to (deal) with that kind of stuff so I didn't really know. I just thought she was weird. I thought she was a psycho. She was nuts…I didn't even know if it was weird, I just didn't think, uh, I just didn't feel something, uh, I felt something wasn't right. You're a kid so you can't really grasp or understand it. You just knew something wasn't right. You just have that instinct, that intuition.

Karen recounts how she began to think there was something wrong with her mother when she became hyper-religious, although it took her quite a while to distinguish this as mental illness:

> My mom was 35…My mom was going to church every single day. And so (seeing) that as a 10-year-old is totally weird…She also was spending a lot of time in her bedroom with the door closed, with the shades drawn and she had like you know spiral bound notebooks…dozens of them and she was writing in them all the time and they were starting to pile up around the perimeter of her bedroom…and sometimes when she would come out of her room, she'd be at the kitchen table writing …and it was like this whole Jesus talk (her writing) and I just thought this is totally weird…that's for Sundays. It didn't make sense…and that made me as a child uncomfortable because I started to see my mom change into this thing that I didn't understand and I didn't like it…And then when we moved to Carver when I was about 13 and she was (still) spending a lot of time in her room sleeping or writing in the notebooks. She was (still) going to church a lot, but she would go there and stay there and pray…She was worried, to put it bluntly, about the states of my and my brother's souls…She seemed to be a little paranoid about what we were doing and who we were hanging out with.… the

> biggest thing really was the fact that she was spending so much time in her room sleeping…She'd stopped doing the laundry and the dishes…The upkeep of the house started to get really gross…and there was clutter. There was so much clutter! And that embarrassed me having friends over…she would take a piece of cardboard and she would write, 'Jesus is my savior,' and she put them all over the house so that everywhere she looked she could see that…My brother and I were like something is really wrong, this is not normal …

Robin's mother became agitated and depressed after she and Robin's father divorced when Robin was nine. She had trouble sleeping at night and would be up until three or four in the morning banging cabinets and yelling. The divorce forced her to go back to work and she found a job as a clothing buyer for a department store that had flexible hours. (Robin thinks if not for the flexible hours, her mother would have lost the job quickly as she could not get up in the morning). Her mother soon started acting suspicious of people and became more vigilant about knowing where her children were and who they were with. She then began doing automatic writing, claiming that spirits of the dead were coming to her and communicating through her. Then one day she declared that she was "the son of Jesus Christ" and predicted that after she died that "time would run backwards" and she would "return from the dead." Robin did not think this could be true, but as an impressionable young child she always "had that little but of doubt" that maybe what her mother was saying was true.

Robin did not feel that she got much support from her older sisters in understanding that her mother had a mental illness. They never talked about it as each of them seemed to exist in their separate orbits. She and her middle sister had never gotten along well and her oldest sister was a teenager at the time her mother became ill in the 1970's and was almost never home. Robin says she was typically off pursuing her "…Quaalude-hazed, marijuana-smoking existence with her friends." Her friends sometimes came to the house and did drugs in the backyard and Robin's mother incorporated them into her delusions, saying that they were "the descendants of the disciples." Some of her sister's friends played along with her because they were high on drugs and Robin thinks this may have helped reinforce her mother's delusions.

Walking on eggshells: Daily life with mother. Several participants used the phrase "walking on eggshells" to describe their daily experience of living with their mothers due to their mother's sudden mood changes. They discussed that their mothers were most often displayed only negative symptoms of schizophrenia such as affective flattening and social withdrawal. Their mothers would sit alone quietly staring into space. Most would chain smoke cigarettes all day. They might complete a chore or two in the course of the day that they could do with minimal effort, such as putting in a load of laundry or unloading the dishwasher, but in general mothers were disorganized in their attempts to keep their household. The wet laundry might be forgotten for days, the clutter would build up all around the house, as Karen described, and unless someone else in the family did it, the household chores would generally not get done. As children, participants reported that they were chronically upset and angry about their mothers' lack of doing things for them and their general lack of attention and emotional response to them. However, as they adapted to their mother's ill persona, they simply came to expect less and less from her and started doing more for themselves. This may be part of an accommodation process on the children's part that would naturally help decrease levels of stress in the household.

Participants' mothers often displayed sudden, unpredictable mood shifts and temper outbursts often with no logic to them. Communication was difficult with them.

When trying to converse, mothers were prone to digression and to jump from topic to topic tangentially. Most participants also witnessed their mothers responding to visual and/or auditory hallucinations. It was not always clear whether their mothers were talking to one of the family members or to someone imaginary.

Mothers sometimes tried to get the participants and their siblings to adhere to their delusional beliefs, such as in the example of Robin's mother trying to convince Robin of her delusion that sprits of the dead were coming to her at night to dictate their thoughts. As a child, Robin was unsure whether to believe the things her mother was saying or not. She didn't think they could be true but she always had a small bit of uncertainty. As she shared a bedroom with her mother, she would sleep with the covers pulled all the way up to her neck out of fear that their might be spirits coming to their room all night to talk to her mother. At the time of her interview, she reported that she continues to have a post-traumatic type response to any small noise in the house at night.

While the majority did not fear any physical violence from their mothers, they learned to be hyper-vigilant around them due to their mothers' sudden mood shifts and unpredictable verbal outbursts. For example, Maya described how she had to constantly keep her radar up around her mother:

> There were times when she would get so mad…I could see it in her eyes. There was just something about her eyes that just freaked me out. And so the counselor that I went to see from the time I was really little, she said I got to be really good at reading people because mom's moods would just shift… I guess I was always on guard because, for example… mom told when I was little… "If I get too mad, you just tell me, 'Mom, you're acting like a bear,' and I will know that you're scared and I will back off." And this was one of her o.k. times… so I was like o.k. And one time she got really mad, I don't remember what I did—maybe I didn't even do anything—she just got upset… and I'm crying and because I'm so scared…I tell her, 'Mom, you're acting like a bear.' Well, that was the wrong thing to say. She got even more mad and yelled and screamed… And so I just had

> to learn what to do, like what to say, when to retreat, when to be quiet, when to kind of acquiesce and just be like, ‘O.K. (to whatever she said), you know?

Carol described how unpredictable and even violent her mother could be. When she was about six or seven her family had just moved to a new small town. Some children started teasing her and throwing rocks at her and she retaliated. The mother of the other children yelled at Carol and then she and Carol’s mother got into an argument. Her mother then took off her high-heeled shoe and beat the woman about the face and head with it until she was dazed and bleeding profusely. Carol felt traumatized at witnessing this as she saw what her mother was capable of. She thinks the woman did not press charges because she was too scared of her mother. Carol also felt responsible for her mother’s behavior because she had helped start the incident by throwing rocks.

In the home too, Carol constantly felt she had to be on eggshells around her mother. Her parents would argue almost daily and their arguments would frequently escalate into both parents hitting each other or her mother throwing objects and breaking furniture. Her father would often get the worst of it. One time her mother hit him in the back with a board with nails sticking out of it. He made Carol help him clean out the wound as he couldn’t reach it, fearing that if he went to the doctor her mother might be arrested. Another time, her mother went after him with a knife and he picked Carol’s infant sister up and held her in front of him to protect himself. As her mother was already coming forward with the knife, she couldn’t stop in time and accidentally cut the baby. (Years later, her sister asked her how she got the scar on her chest and Carol told her the story). At night, Carol’s mother would typically be awake until all hours, screaming at people who were not there, waking the family and the neighbors as well. She would hit

Carol and the other children even for minor offenses such as chewing food with their mouths open.

Managing anger, frustration and shame. Most participants discussed that they often felt intensely angry and frustrated with their mothers due to their inability to function as mothers to them post-onset of schizophrenia. As children (and later as teens) having not yet come to accept the fact that their mothers were impaired by a debilitating mental illness, they sometimes felt that their mothers were purposefully being withdrawn or performing odd behaviors to provoke other family members. As Carol said, "I just thought she was weird." She thought that her mother was purposefully trying to make everyone around her feel miserable. Steve described the mixture of anger and shame that he felt toward his mother for her illness:

> Now that I think about it, I was ashamed that my mother was ill and I was angry at her, both. I felt she had abandoned me and let me down. She hadn't been there for me and I felt like I practically got myself through the end of school single-handedly.

Often participants displaced their anger onto their siblings or their fathers. For example, Karen was furious with her brother for emotionally "checking out" from the family and leaving her to deal with their mother's issues alone. She wanted to share her feelings with him, but he never wanted to talk about it. Carol blamed her father for his general emotional unavailability and felt this was a contributing factor to her mother developing of schizophrenia.

Shifting family roles and dealing with parentification. Once mothers developed full blown symptoms of schizophrenia, they were no longer able to manage their homes and their children without assistance. Even when the father was in the home or a grandmother or aunt would come in to check on things, many household chores were left undone and younger children were often left unsupervised. Thus, several participants became parentified by their mothers in that they were forced at a young age to actively take on a parental role in running the household and taking care for their younger siblings (and sometimes their mother as well). All found this to be a highly negative experience as they missed out on fully being a child.

Donna first became parentified by her mother when she was only five years old. As the oldest of five siblings, she recalls that every time her mother had a new baby, “I was (the one) holding the bottle! I remember standing there and holding all the bottles for my brothers and sister. And the more kids she had, the more bottles I held…”.
When Donna was six, she so wanted to play with the six-year-old girl who lived across the street, but her mother would always say no because she needed her to watch her younger siblings. Her mother would sleep during the day as she was typically up all night screaming her prayers and banging things. Lacking an actual friend, Donna created an imaginary friend to play with whom she kept active in her imagination for a number of years. She notes sadly that she never had the opportunity to make a real friend until she was in high school. In retrospect, Donna feels that while she did not get any real nurturance from her mother, she thinks that what fed her emotionally was caretaking her younger siblings, even though this often felt like a burden. It was the dual aspect of this parentified role that set up the main tensions of her adult life between caretaking and self-definition.

Similar to Donna, Carol acted as the main caretaker for her two younger siblings throughout her childhood. However, she did not build her identity around the role. Her family situation was complicated by the fact that her father, who had been a milkman and a shopkeeper, was also a con man of sorts and very controlling. He would constantly run scams on people and would often force Carol or other family members to dress up in disguises and take part in them. One scam that Carol continued to express hurt over during her interview, was that he would always bring her to all her relatives' houses when it was close to her birthday. After the relatives gave her some birthday money to buy herself a gift, both her father and mother would always take the money from her for themselves to pay bills. They would laugh about how they had conned the relatives without giving a second thought about having cheated Carol out of her gift money.

Typically, if parentification occurred, it happened to the oldest child, but this was not always the case. Robin was the youngest in her family, but she became 'the parent' to her mother when she was sixteen because her older sisters abdicated the responsibility to her by leaving the home as soon as they were old enough to do so. Robin feels that the main emotional issue for her has always been that there was something fundamentally missing in her early relationship and interactions with her mother. She was constantly trying in vain to get her mother's attention and acknowledgement that she was loved and valued. She explained:

> I always tried to earn her respect, always, always. I mean literally, she would tell me to do something and I would try to do it in order to please her and try to gain that respect and try to get some validity out of my life.

Her desire to be seen and validated by her mother kept her locked into the caretaking role with her. Even after her mother rejected her by sending her to live with her father, after three years with him Robin still longed for her mother's attention and approval. When her sister moved out of her mother's home leaving an open bedroom, Robin jumped at the chance to return to her mother. She then got stuck in the caretaking throughout her later teenage years.

Adolescence exacerbates anger/ conflicts between offspring and mother. Several participants described incidents where the increased impulsivity of adolescence combined with their mothers' unpredictable behavior to almost lead to tragic outcomes. For example, one night Carol heard her mother screaming at her younger sister and Carol, tired of her mother's rages, felt like, "I can't take this anymore," and "just snapped." She grabbed a knife and ran downstairs, explaining matter-of-factly, "I was going to kill her and I think I could have done it." Her father tried to stop her and she pushed him down the stairs. She ran to the kitchen to attack her mother, but her father had managed to slam the kitchen door shut between them. Carol banged on the door screaming threats at her mother while her mother, never one to back down, grabbed a kitchen knife and was stabbing the door from the other side, threatening to kill Carol. Later that night her father, fearing a potential tragedy, took her mother and her younger sister and moved out, leaving the house to Carol and her 14-year-old brother. As soon as their parents left, they ran through the house happily singing, "Ding, dong the witch is dead!" from the Wizard of Oz.

Not all participants had examples as dramatic as this, but they indicated that their and/or their sibling's adolescent rebellions when combined with their mother's mental illness made for unique levels of conflict within their families. Other examples are Steve's middle sister as a teenager continually getting into arguments with her mother where they were both "always right" and then the fights would turn physical. Robin's mother would beat her 17-year-old sister with a yardstick for continually breaking her curfew while at the same time she allowed her and her friends to do drugs at their home with no consequence whatsoever.

Mourning the pre-illness mother /dealing with ambiguous loss. Codes for participants' mourning the loss of the pre-illness mother appear in Table 5. Codes included: *bargaining with God, feeling a lack of mother's love/attention, feeling constrained in expressing feelings of loss to others (due to stigma), feeling embarrassed by ill mother's appearance /behavior, feeling family is immobilized/ paralyzed, feeling responsible/doing penance for mother's illness, feeling that early mother died, feeling that post-illness mother is a different person, mother was not really there for us, trying to be extra good (to make mother better)* and *using food as solace (for loss of mother).*

Participants discussed that their mothers post onset of schizophrenia were "like a different person" compared to their pre-illness mothers. They had to deal with the loss of the more nurturing, pre-illness versions of their mothers. While their mothers post-onset of schizophrenia were still physically present in body, they were no longer emotionally present. Offspring struggled to make sense of the drastic personality shifts they saw take place in their mothers. Typically, their mothers would remain withdrawn and pre-occupied with their internal thoughts. Many evoked the image of their mothers staring into space for long periods or chain-smoking cigarettes while mumbling or sometimes laughing to themselves. Often, their mothers were not even mentally operating in the same reality as their children due to paranoia, delusions and/or hallucinations. Holly described her mother's emotional absence as, "She just wasn't really there for us." Donna put it more bluntly, "My mother died to me." To confuse them further, offspring might from time to time see a fleeting glimpse of the former loving, reliable mother that would just as quickly disappear.

Since Maya's mother developed schizophrenia before she was born, she had never known her pre-illness mother. Nevertheless, she still felt that she had to grieve the healthy mother as she would have imagined her (based on what she had learned about her pre-illness mother from her father and other relatives). She described how her grieving process seemed to take place in stages:

> I guess you could say I kind of went from this embarrassment phase of her, to an almost hatred phase of her to almost, you know, a respect (phase) for her to be able to (doesn't finish)… (sighs). Like I just can't imagine what her life would have been like… It's sad that it happened the way it did. I would have loved to have had a relationship with my mom. (I) would have loved it! You know, I guess I'm never going to have that…

Here we can see Maya moving from a denial/avoidance phase (what she called "embarrassment") through an anger phase (what she called "hatred") through a moving toward acceptance phase that her mother has struggled with a severe mental illness (what she called 'respect'). At the end, she imagines how wonderful it would have been had she had a real relationship with her mother and then ends with a final acceptance of loss, "You know, I guess I'm never going to have that."

In the Discussion, we will further explore the grief process of offspring and the possibility that they pass through the five stages of grief (Kubler-Ross, 1969) in dealing with the loss of their pre-illness mothers.

For some participants who were parentified as young children, the loss of their pre-illness mother not only entailed dealing with the loss of the mother, but also a loss of themselves (or themselves as they might have been), as they had never been allowed to be fully children. Donna describes how this was painful to her on two levels:

> I then took on my grandmother as my mother… my mother died to me. Because I was the do-er (around the house), I became a 'thing' (to my mother) and that's where you can see me eating and looking for solace in food… there was no affection (from my mother), affection was gone. I was a thing (begins to cry)… never a person with feelings or needs.

While grieving the "death" of her pre-illness mother, she also had to deal with the depersonalization of becoming her mother's "do-er" and having her own feelings and desires denied.

For all participants, the loss of their pre-illness mother was confusing due to its ambiguous nature. According to Pauline Boss (1999), ambiguous losses are harder to process than the actual death of a loved one. She discusses how family members of loved ones who are lost ambiguously may become "frozen" in their grieving process (pp 1-25). The theme of ambiguous loss will be elaborated in the Discussion section in relation to Boss's (1999) theories.

Feeling responsible for mother's illness. As young children typically view situations with themselves at the center, the majority of offspring indicated that they had felt responsible as children for somehow causing their mother's schizophrenia. For example, Holly described how as a child she would try to get better grades so that her mother would be happy instead of sad and withdrawn. Other participants explained that their striving to be "extra good" was part of their "bargaining with God" to make their mother better. When they achieved good grades and their mothers did not change they then felt "anger at God" as well as at their mothers. For many their feeling of being responsible seems to have continued, mostly unconsciously, into adulthood. This will be discussed further in the Lasting Effects/ Adult Functioning section.

Interestingly, Maya (the only participant to receive therapy as a child) could not recall ever feeling that her mother's illness was her fault. She supposed that because her mother already had schizophrenia before she was born, that this may have helped her to avoid blaming herself. However, she felt that the bigger factor was that her therapist and her father, who attended some of her sessions, had told her unequivocally that her mother had a mental illness and that it was not Maya's fault. He father continued to clearly give her this message for years and she feels this made the difference for her.

Mothers' difficulty with self/other differentiation with their children. At least three of the mothers had difficulty with self/other differentiation with at least one of their children and had difficulty allowing their children to become independent. Some of the mothers were reported to have been nurturing to their children while they were dependent as babies, but the mothers then seemed unable to stay close to them once they reached an age when they started becoming more independent. Carol described that her mother's affection disappeared as the children got older:

> …We were told by her family members, her sisters… that she was really affectionate when we were babies, but when we got to the point where we were a little bit older it kind of wore off…I would say about four or five, once we were able to do stuff… And she's still like that, she loves little babies, loves them! She just doesn't like older kids...

Donna similarly reported that prior to age five she had her mother's positive attention and affection. She could recall her mother reading with her and being proud of her for being able to make the sounds the animals made in the storybooks. All of this then disappeared around age five when, as described above, her mother turned her into her “do-er” to take care of her younger siblings.

Maya, an only child, said that when she lived with her mother prior to age ten, her mother never allowed her to make any choices for herself. Her mother would always decide what she would wear and what she would eat and what she would play with. When she first went to school, she had so much anxiety about separating from her mother that when her mother dropped her off in the morning she literally vomited every day in front of the school for over a year. Her mother then put her on the bus to change this routine, but she followed the bus in her car every day until the bus driver made a complaint. The enmeshment with her mother left Maya feeling unable to make her own decisions or to communicate her wishes to other people. She feels this resulted in her having social difficulty with peers in her grade school years. Fortunately for her, when her father took custody of her when she was ten, with advice from her therapist, he began to teach her to make her own choices and to become more independent. Despite this, even as an adult, Maya reports she continues to have difficulty making her own decisions. While she was not dating at the time of her interview, when asked what qualities she would look for in a boyfriend, she responded without hesitation, “Someone who is decisive,” in the hope that he could counterbalance her difficulty in that area.

Robin reported that her mother shifted from being disengaged with her in her early childhood years to being enmeshed with her as an adult. The youngest of three girls, Robin feels that her mother pretty much ignored her from ages one to five in favor of doing things with her older sisters. She recalls “constantly” being left to play on her own in her playpen until she was at least four. She does not think her mother was mentally ill at this point as her mother kept the house, was the leader of her sister's girl scout troop, had friends, went out with her father every Saturday night and played the organ at church services.

Some mothers did splitting with their children where they treated one child as all good and another as all bad. For example, Steve was "the golden boy" in his mother's eyes who could do no wrong, whereas his mother was constantly screaming at and arguing with his middle sister whom she treated as "the black sheep." Similarly, after Robin's mother became mentally ill when Robin was nine, her mother created a split between Robin and her middle sister, Jeanine. She started treating Robin "like the maid" while she treated Jeanine, 'like the princess." Robin recalled:

> Every spaghetti night, my mother would leave that big dirty sauce pot for me to scour. I remember scrubbing and scrubbing that thing trying to get it clean. And it never was Jeanine's turn and if I (complained) about it out loud, then my mother would come and slap me in the back. She used to wear this big amethyst ring and that would hurt when she hit me with it on. I mean I wasn't really hurt, but it was the shock of it because you would have no warning it was coming…Jeanine would be lying on the couch and she would suddenly demand,"Get me a glass of water." And I would be like, "Get your own water." Then my mother would scream at me, "Go and get your sister a glass of water!" She never told (Jeanine) to go get it herself, and she never told her to get me anything.

As time went on, Robin's mother's rejection of her became so thorough that when Robin was thirteen, her mother found a new, smaller apartment for her and Jeanine to live in and told Robin she had to go live with her father because there was no room. After three years with her father, this shifted when her sister moved out on her own. Her mother then got Robin to move back in with her and began treating her as an extension of herself into Robin's early adult years. If Robin was not waiting on her mother, her mother farmed her out to watch her oldest sister's children. Robin said that she stayed with her mother because she was so locked in to seeking her approval which her mother always withheld from her.

Variability in mother's course of illness. All participants reported that their mothers' symptoms of schizophrenia had a variable course over time. Some said simply that their mothers had "good days and bad days." Good days were when their mothers were calm and not visibly responding to delusions or hallucinations. In a few cases, good days were even better than this where mothers might even take part briefly in family conversations, although mothers were more typically focused on events in the past than in the present. Maya described how her mother could even be quite functional as a parent at times:

> … I really feel like there were periods of time where she seemed normal. You know what I mean? Like not completely normal, not what I envision a normal mother to behave like, but, to the point where I wasn't afraid of her and where I wasn't embarrassed by her. And those times, yeah, I mean she was able to help me with my schoolwork, and to teach me the flute and to instill a good sense of manners and respect for people.

Steve described that his mother always continued to guide him and his sisters in their educations. In periods where she was more lucid, neighbors would still come to her to seek her guidance about their children's educations as she, having been the head of a school, essentially knew everything about local schools and programs.

Karen described that when her mother was not pre-occupied that she could be empathetic toward her at times. For example, Karen would sometimes get teased in middle school for being unusually tall. She remembers coming home crying on several occasions and her mother was able to respond supportively, telling her to lie down on her bed and to "cry it out" while her mother sat next to her and gently rubbed her shoulder. It should be noted, however, that retaining the occasional ability to express empathy to their children was not common for all participants' mothers.

Feeling powerless: Difficulty obtaining psychiatric services for mother. A chronic problem with individuals with schizophrenia is that they have difficulty in recognizing that they have a mental illness and are often resistant to seek and to maintain psychiatric services (Leucht and Heres, 2006). This poses a considerable dilemma for spouses and their children who wish to obtain help for them. Due to their mother's resistance to treatment, participants reported "feeling powerless" to get their mothers the help they needed both as children and as adults. They felt they could not seek help for their mother without their father's consent. The unwritten rule within the family to not discuss their mother's illness was a significant obstacle to any productive discussions regarding seeking services for mother. Carol reported getting very angry with her father because he would sometimes talk to her as if she were an adult about wanting to get her mother "some help." She would urge him to take her to a doctor or to call an ambulance but he would never follow through, saying that "there would be hell to pay" if he did this without her mother's consent. Other participants reported that their fathers similarly would not force their mothers to get help against their will. This created a Catch-22 type of situation as the mothers, unable or refusing to recognize that they were mentally ill, would never consent. A limitation of the study is that fathers were not interviewed, so it is hard to discern what their thought process was regarding seeking or not seeking services for the mothers. This is an area for future research.

Only one participant, Steve, when he was sixteen was able to successfully convince his mother to go willingly to the hospital for a psychiatric evaluation. He saw that her functioning was deteriorating as she was refusing to eat and to leave the house. He sat with her calmly one morning, described her symptoms to her in concrete terms, and told her that she was sick and needed psychiatric help. When he returned home from school that day, he got a phone call from a family friend who told him his mother had checked herself into the hospital. This successful intervention appears to be the exception, not the rule among the participants.

Outreach from the psychiatric community was virtually non-existent in most cases. Only one participant, Carol, had the experience of a mobile crisis team coming to her home to evaluate her mother, the result of a neighbor calling in a noise complaint regarding her mother’s screaming. Carol had almost been at her wits end with her mother’s behavior and was thrilled that help had finally arrived. However, it turned out to be a crushing experience. Her mother managed to pull herself together for 10-15 minutes of normal conversation with the evaluating doctor, after which he told the family that she seemed fine to him. In the interview, Carol’s indignation was still palpable as she questioned how the doctor could reach this conclusion after viewing the furniture her mother had recently smashed and the religious graffiti she had spray-painted all over the walls.

Delays in diagnosis and hospitalizations of mothers. The information in this section was mainly taken from the written questionnaire. Despite their resistance, seven of the eight mothers eventually had psychiatric hospitalizations. Four had five or more hospitalizations, one had three hospitalizations, one had one hospitalization and one was never hospitalized. The age of the mothers at their first hospitalization ranged from 32 years to 63 years with a mean age of 41.4 years. Of the participants whose mothers were hospitalized in their childhoods, they reported that their fathers generally stayed with them during their mothers' inpatient stays. One reported that her paternal grandmother cared for her during her mother's one inpatient stay.

The average age of the mothers when they first received a diagnosis of schizophrenia from a medical doctor was 41.4 years with a standard deviation of 10.9 years and a range of 30-57 years. The mean delay between mothers first displaying noticeable symptoms and receiving a diagnosis of schizophrenia was 5.7 years for all participants' mothers (excluding one who was never treated) with a standard deviation of 6.8 years and a range of 0.5 to 16 years. However, there was a significant split between mothers who received treatment almost immediately (typically due to quick onset breakdowns) and those whose treatment was delayed (typically due to a less dramatic onset of symptoms). For three of the mothers who received a diagnosis of schizophrenia within two years of first showing symptoms, the mean delay was only 1.25 years. However, for three other participants' mothers who generally had a slower onset, the delay between initial onset and first receiving a diagnosis was a mean of 12.7 years with a standard deviation of 3.1 years and a range of 10 to 16 years. The delay for the mother who was never diagnosed was 14 years at the time of her death (from an untreated medical condition). The mean age of all the children participating in the study when their mother first received a diagnosis of schizophrenia was 16.8 years with a standard deviation of 11.1 years and a range of 3 to 36 years. In four of the eight cases, the window of opportunity to diagnose and treat the mothers while their children were still minors was entirely missed.

Medication and treatment of mothers. Responses to the written questionnaire indicated that seven of the eight mothers with schizophrenia were eventually prescribed psychotropic medications and five of the seven had repeated periods of non-compliance with taking them. Participants' ratings of their mothers' typical medication compliance were one excellent, one good and five poor. One mother also had at least one treatment of electro-convulsive therapy in addition to medication which was temporarily effective in relieving her depressive symptoms. One mother never received any form of psychiatric treatment or medication. She died a relatively early death from a treatable medical condition that she had neglected, a long term consequence of her general paranoia about seeing doctors.

Coping mechanisms. The information from this section is taken from Table 6, "Codes for adapting and coping with mother's active illness." Codes included*: adopts an alternate family (friend's family), avoidance of negative feelings /suppressing, bonds with peers (whose parents also have MH/ alcohol issues), compartmentalizes family life from school/peers, confides in best friend, confides in stable adult, denial/ positive use of denial, enjoys helping others/ enters helping profession, focuses on escaping family (to college, army), focuses on personal goals, immerses self in peer group, immerses self in school, immerses self in sports/activities, leader of peer group /likes being in control, making a conscious decision to break away, personality shifts from shy to gregarious, prefers male friends (as means of limiting social conversation re: mother), Reading books (as outlet/escape), staying out of house as much as possible, teaming up with siblings to run household, tells self situation is temporary /stays future-focused, uses humor as means of bonding with others,* and *uses humor to keep others at a comfortable* *emotional distance*. This section is also supplemented with information from psychobiographic analysis of interview questions 8-15 (Appendix A) and from the Sources of Support section of the written questionnaire (Table 1).

Denial, avoidance and suppressing feelings. Several participants described that denial and avoidance were adaptive for them, at least in their early years of dealing with their mother's illness. Carol, when asked to describe the personal qualities in her that allowed her to deal with her mother's schizophrenia, replied without hesitation, "Denial and avoidance (laughing)." Most participants agreed that their denial and avoidance was adaptive, but believed it to be more of an unconscious strategy that helped them control their anxiety, rather than something they did by plan.

Donna responding to the same question said: "Logic, Suppressing, Avoiding." As a child, she had watched the television show, Star Trek, and had become fascinated with the character, Mr. Spock, admiring his reliance on logic and his ability to suppress his feelings. She used him as a role model and found that "by using logic to detect where (her) mother's ideas were illogical," and by "suppressing (her) own feelings" that she could more easily deal with her mother. She cited the example that if one of her younger siblings asked her why their mother was doing this or that strange thing, she would calmly reply, "Because she's crazy and it doesn't make any sense." Her ability to maintain her equilibrium in this way served as an anchor that also helped her siblings deal with their mother's unpredictability.

Drive to succeed, making use of social skills and humor. Responses on the sources of support questionnaire (Table1) showed that participants gave "My own drive to succeed" the highest mean rating (4.6 out of 5). They described how they felt that due to their mothers being mentally ill, that there was no parent behind them to guide them, support them or to push them toward their goals. Therefore, they set their own goals and pushed themselves forward. Their common motivation was to find a way to escape living with their mother, although their desire to leave was often complicated by their wish to save or to rescue their mother. Participants who had been parentified also felt guilty about leaving their younger siblings behind with their mothers. In Carol's case, she arranged for her younger brother to go live with an aunt in another town when she left home for the army at age sixteen, as she felt he would not be able to withstand the psychological stress of their mother's behavior without her there. Each participant had to drop (at least temporarily) the fantasy of saving their mother and make a conscious decision to break away from their families in order to achieve something in their own lives. As Carol described, "As a kid I always told myself…I'm not going to live like this when I get older. I'm going to get out of that (dysfunctional family) system as soon as I can." Similarly, Holly, the oldest in her family who was a caretaker for her younger siblings had to trust that her father in the home and visits from her aunt and grandmother would be enough for her siblings when she left for college. She said, "I just had to go. I couldn't stay. I would have gone crazy myself."

All eight participants presented as intelligent, perceptive and talented people with good senses of humor. Like Karen, several described themselves as being "total people person(s)." The majority displayed excellent social skills and discussed how their ability to make and keep friends has served them well in life. Several have played the roles of leader, social organizer, counselor and/or comedian in their groups of friends. Several including Carol and Steve said that their sense of humor was a great asset for them as it helped them bond with others. Steve and Karen also discussed being aware through their therapy that they use humor as a means of emotional distancing as well. While this was adaptive for them as children, it is not always as adults, as Steve noted that his constant default to humor would frequently bother his wife who wished him to be more open with her.

Teaming up with siblings to run household. Some participants were able to work with their siblings to keep their households running when their mothers were unable to do it. For example, Steve described how when his mother had her first breakdown when he was sixteen, he and his two younger sisters became “a team” that worked together to keep their household running. He said:

> Well, we had starting to do some of the things in the house after my parents divorced when I was 11 and then it just got to be more…But, my sisters and I, I mean, we were a team (said proudly). Whatever needed to get done, we like organized ourselves and did it. We would clean the house and after the meals we would clean the kitchen up and do the dishes. We made a schedule for whose turn it was and followed it… and we cooked too. I think we had a schedule for that as well, although my mother would still cook sometimes. That was like the one thing she would still do, but that was not every night…and we did the shopping, which was rough sometimes because we had gone from middle class to poor, I guess. I mean we were never destitute…one of my sisters worked in a grocery and kept us in vegetables…and we would wash the clothes in the house and hang them up to dry… so we got it all done somehow and we were really proud of ourselves…

Immersing oneself in school. All eight participants reported that one of their main coping strategies was immersing themselves in school. School was a place where they thrived as most participants reported having average to above average intelligence and very good to excellent grades. They enjoyed the positive attention they got from their teachers and were eager to please them by working hard. School offered a different reality that they could keep almost completely separate from their home lives. For example, Carol threw herself into her schoolwork and was quite a good student, winning a number of academic awards. She enjoyed that school was a place where she was known and where people valued her for her abilities. It was a place where her mother’s issues could not intrude.

Carol, and other participants such as Donna and Holly, while unable to cite a specific teacher, counselor or coach that they had a special relationship with, emphasized the importance of their school as a whole as a source of stability in their lives. They liked being around the stable adult figures of their teachers, although they preferred to keep a comfortable emotional distance from them. Having access to emotionally healthy adults in school gave them better adult role models than their mothers presented. It also provided them with needed experiences of adults who were able to give them attention, who could show them emotional availability, who displayed warmth and humor, and who also provided them with the structuring and discipline that their mothers were unable to provide.

Robin, unlike some of the other participants, did not initially do well in school. Her language was delayed, she believes, due to her mother not interacting with her enough when she was a toddler. She had trouble learning to read, but her second grade teacher gave her so much individual attention that this made a big impression on her and Robin’s reading improved steadily. She then decided that she would become a teacher when she grew up and ultimately did.

All of the participants had similar positive attitudes about school. Their ability to thrive in the school environment put them on a positive trajectory toward college and toward success in their adult lives.

Compartmentalizing home life and staying out of the house as much as possible. Compartmentalizing their home life from their school life and social life with peers appears to be a strategy adopted by all participants. Participants tried to stay out of the home as much as possible to limit their exposure to negative interactions with their mothers. Participants would never invite friends home due to their fears that their mother might display odd behaviors in front of them. Karen learned this the hard way as a teenager when she once brought a potential boyfriend home to listen to music. Shortly after they arrived, her mother began screaming and wailing from another room. Karen quickly learned to never bring people home. Similarly, Steve recounted that since their house was on the main street to his sisters' school that a number of their friends would gather in their living room in the mornings to walk to school together. However, when his mother appeared one day talking to herself and looking at everyone strangely, his sisters quickly put an end to this morning meet-up. He counted himself lucky because his school was ten miles away and all his friends lived close to the school. It thus made sense that he should visit them at their houses after school rather than have them travel so far to his. He always liked visiting his friends' homes because their mothers were nice to him and because he didn't have to worry about his mother embarrassing him in front of his friends. Some participants also reinforced the separation between their school/social lives and their home life by not informing their mothers of events at school they were taking part in. For example, Maya would never tell her mother when her band was performing for fear that she might show up and make a scene. As she got older, she would not even tell her mother her friends' names for fear her mother would look them up in the phonebook and show up at their houses demanding to see her.

Involvement with sports and activities. Laura, Holly and Karen emphasized the importance of their involvement in playing sports as an alternate focus that was for the most part separate from their home lives. Laura discussed how being on the swim team as a child kept her "focused on (her) own goals" and allowed her to at least temporarily put her mother's problems out of her mind. She and her sister also participated in numerous activities at the local community center from basketball, to ballet, to tap dance. "You name it, we did it," she said. Her mother, despite her active illness, managed to shuttle them back and forth to all of these activities. This focus on participating in sports in Laura's life carried through to her swimming competitively at the high school and college levels. Post graduate school, she became involved politically in saving her neighborhood's local pool from closing because she said significantly, "I literally grew up there."

Holly ran track and cross-country on the boys' team. She liked the competition, the meditative aspects of running and the feeling of belonging to a group. Over time, her coach became a mentor to her and she was eventually able to confide in him about her mother's illness. She appreciated his support and sensitivity.

Karen was a mainstay on her school's tennis and volleyball teams and she also played basketball for a season. Her brother was a star athlete on his teams. Karen's mother, at least in the early stages of her illness, still managed to attend all of Karen's and her brother's games. She did not interact socially with the other parents, but mainly sat alone quietly and did not draw attention to herself. While Karen sometimes worried her mother might make a scene, on another level she appreciated that her mother made the effort to be there. In addition to playing sports, Karen acted in student plays and was gifted as a musician, spending the majority of her free time at home practicing the piano. This will be discussed further in the Playing Music section below.

Sources of support. Data for this section is taken from interview question 20 (Who and or what were your sources of support in your childhood during the time period when your mother was ill? Who and or what kept you going?). This is also supplemented with data from the supports questionnaire. Codes appear in Table 7 and included: *Bonding with peers whose parents had issues (MH, alcohol), caretaking/ doing things for others (heals self), father/ relying on "healthy" father, friends (early/ middle childhood), friends (adolescence), friends (adulthood), pets (giving/receiving unconditional love /affection), playing music (i.e. piano, flute), pursuing a dream /goal* and *siblings (feeling support from their presence)*

Relying on 'healthy' fathers. Despite the typical state of denial within the family post-onset of mother's illness, most participants felt that having a mentally healthy father in the home (or living nearby in cases of divorce) was a crucial source of support to them. Fathers received a relatively high rating of 3.6 out of 5 on the sources of support questionnaire. The fathers of the participants in general showed a high degree of dedication to their wives and children. All eight participants had fathers in the home for at least their early childhood years. At the time of interview, three of the eight fathers remained married to their wives with schizophrenia, often at great personal cost to their own emotional lives. All five of the fathers who separated from or divorced their wives with schizophrenia remained involved with their children. There was a good deal of variation in how the eight participants experienced their father's support. Three found their fathers invaluable and gave them a 5 out of 5 rating. Four scores were in the mid-range of 2- 4. The lowest rating given was a 1 out of 5 due to the father's overly controlling nature and the participants' avoidance of him.

In retrospect, the majority of participants appreciated their father's presence in their lives and expressed that they may not have achieved a normal adulthood had their fathers not stood by them. Nevertheless, many as children had experienced long periods of anger toward their fathers, felt with particular intensity during their teenage years, because their fathers had typically been unwilling or unable to get professional help for their mothers.

Fathers of the participants tried to fulfill the traditional roles of breadwinner, father and husband in their families, and often did so heroically with little positive reinforcement from anyone. They also had to contend with wives who had active schizophrenia. This sometimes forced them to expand their roles in the families to include duties that mothers more typically perform. Fathers also frequently had to contend with such unusual circumstances as being incorporated into their wives delusions and having to defend themselves against their wives charges that they were conspiring with the CIA or the FBI against their them or having an imagined affair with their secretary or neighbor. Mothers acting on their delusions sometimes had real impacts upon the fathers in their workplaces. For example, Carol described how her father lost several jobs because her mother had burst into the workplace to scream accusations at him.

Karen described how her mother was unable to take part in the many social functions that her father's executive position required. Karen then began to fill her mother's role by accompanying him to his work events such as his annual office Christmas party. On a positive note, some of the people her father worked with were aware of his wife's mental illness and were quite supportive of him, admiring his dedication to his family. A possible negative to Karen's shift in role to her father's social companion, was that when she got to college, she felt too mature for the typical college social life of wild parties and drinking.

While no formal data was taken on participants' fathers, there were indications that they were at high risk for depression. The fathers coped with their wives' mental illness in various ways. Similar to their children, they typically started their coping process with denial, followed by avoidance. Holly describes how after her mother became mentally-ill, her father became a workaholic in order to stay out of the home as much as possible:

> (My dad) threw himself into his work and then he became not around too much. He lived there (in the house with us) and he paid the bills. It was obviously hurtful for him to see his wife in that (mentally ill) condition. So, he'd pretend like it wasn't there and he'd throw himself into his work. He'd be gone like 12 or 13 hours per day.

Holly experienced his typical absence from the home as a second abandonment in addition to the emotional abandonment by her mother. While her maternal grandmother and aunt often came by to give support, Holly still felt it was mainly up to her to keep the home running smoothly for her younger siblings. Despite her father's frequent absence from the home, he remained an important figure of stability to her. Her career choice to retrain in the same profession as her father—real estate agent—seems to indicate that she continues to have a positive identification with him.

A few fathers developed addictions to alcohol or other substances. One of the divorced fathers became what the participant described as a "functional alcoholic" who drank every day, but never missed a day of work. He may have also been addicted to gambling, although she said he set limits on himself and was always able to pay the bills. The participant indicated he had been doing these behaviors during the marriage as well. One of the fathers was reportedly addicted to prescription medications and one was described as “definitely addicted to food—the whole household revolved around food.” The food addiction resulted in obesity, multiple health problems and multiple surgeries.

All of the divorced and separated fathers remained involved with the participants and their siblings post-divorce and were important sources of support to them. Of the five divorced or separated fathers, only Maya’s father went to court to take custody away from her mother when Maya, an only child, was ten years old. She feels that leaving her mother’s home to live with her father completely changed the course of her life for the better. She said somberly, “I can’t imagine what my life would be like if I had stayed with my mother. But, I know it would not have been good.” Not only did it greatly reduce her exposure to social stigma as she was no longer immediately identifiable with her mother, but she feels her father was an excellent parent and was emotionally present, attentive and able to provide whatever she needed.

It is a difficult question as to why the other divorced fathers left their children in the custody of their ex-wives when they knew they were mentally ill and extremely limited in their ability to parent. It is a limitation of this study that fathers were not interviewed as well, but their stories of how they experienced their wives’ schizophrenia would be an interesting area for further research.

Feeling support from siblings’ presence. There were indications that having siblings in the home provided a prophylactic effect to participants in dealing with their mother’s schizophrenia. Siblings received relatively high ratings (mean rating 3.6 out of

5) as sources of support. Participants did not necessarily discuss their mother's mental illness with their siblings, but having them present and knowing they were going through the same issues was reassuring to them as they did not feel alone. For example, the story of Steve teaming up with his sisters to run the household illustrates how he felt they were all in it together. Similarly, Laura had positive relationships with her siblings growing up, although they all tended to spend a lot of time out of the home with their respective friends. She remains close to them even though they now live in different parts of the country by speaking with them on the phone almost daily.

There was, however, a good deal of variability between participants as to their relationships with their siblings. Also, some of the participants' relationships with their siblings changed markedly through time. For example, Karen was best friends with her older brother when they were young but as time passed their differing ways of dealing with their mother's schizophrenia led them to separate into their own orbits. By the time they were teenagers, while Karen was always trying to help and to understand her mother, her brother expressed the attitude of "she's (messed) up, so what do you want me to do?" He would then stay out of the house as much as possible with his friends and, despite being an A student and a star athlete, was often experimenting with drugs. As an adult, Karen is saddened that her brother continues to shun the family to the point that he would not even visit his mother during her last hospitalization. He is currently in his second marriage and has had one child with each wife, but Karen has little contact with him or his family.

Conversely, Robin's relationship with her middle sister is much improved since they were children. As children, Robin had a constant open conflict with her because her mother fueled it by treating them differently—her mother treating her sister as “the princess” and Robin as “the maid.” Robin remained somewhat estranged from both her sisters for several years after their mother died when Robin was twenty-eight. She had resented that they had left her with the job of caretaking their mother by herself. But, after Robin got into therapy at age thirty-nine, she realized that she had never communicated well with her sisters or asked them for help when she needed it. With the support of her therapist, she worked on rebuilding her relationships with them. Her oldest sister did not respond that well because she had become depressed over the years, but Robin’s middle sister responded positively and they have been able to become good friends for almost the first time in their lives.

Donna, a parentified child, while getting some emotional supplies from caretaking her four younger siblings, had difficulty keeping them in line, especially the oldest boy, Bob, who was quite rebellious. The one area where she and Bob worked well together was in diverting their mother from beating their younger siblings. Donna says that Bob would always take her mother on in those situations and end up with the worst of the beatings. As an adult, Bob ended up getting into using drugs and alcohol. Due to this he and Donna are not close. While growing up, Donna had always been closest with her youngest sister, but because Donna essentially raised her, she feels that her sister relates to her more as a mother than as a sister. According to Donna her sister, “blames me, not our mother, for everything that has ever gone wrong in her life.”

Support from grandparents and other relatives**.** Grandparents appear to have sometimes played a supportive role in the lives of the participants, but in general their support was minor (mean rating 2.1 of 5). Reasons for their not being more involved are unclear. However, some participants indicated that their mothers, due to their denial of having a mental illness, had often pushed their parents and other relatives away when they had tried to help them. Nevertheless, some grandparents were directly involved with their grandchildren. For example, when Maya’s father took custody of her, he brought her to live in the house he shared with her paternal grandparents. She had barely mentioned her grandparents in the course of the interview, as it was clear from her narrative that her father was always her main caretaker in that home. Her grandparents were always in a secondary role to him. Similarly, Holly described how her maternal grandmother and maternal aunt would frequently come into the home to clean or to prepare meals, but said they never fully took on a daily parental role with the children. Even with their visits, Holly still felt that due to her father’s being a workaholic and seldom being home, that the main burden of parenting her younger siblings fell on her alone.

Donna had a very positive experience of her paternal grandmother, but a very negative experience of her maternal grandmother. Her paternal grandmother was a godsend to her at age nine when she temporarily moved into Donna’s house to help her father with the children when Donna’s mother had her first breakdown. Her mother had been reversing days and nights and had become hyper-religious. She stayed up all night screaming prayers and waking the household and the neighbors as well. Finally, one day she announced to the family that “red is the devil’s color” and built a big bonfire in the backyard in which she burnt every red object in the house. Her father wanted her hospitalized, but her maternal grandmother intervened and said she would help her daughter recuperate without the help of doctors at her home. She then moved her into a small apartment over her garage.

Donna's paternal grandmother then moved into Donna's house and relieved Donna of all parenting duties with her siblings. Donna reveled in her first experience of being an unburdened child:

> I was not in the parenting role… because my grandmother was and I loved it! It was such a relief to have her saying (to my siblings), 'You sit down, and you take a bath,' and it wasn't my job (any more). Not only could I play, but I could just isolate into myself. I didn't have to be aware (of everything going on) as adults (have to do).

However, when Donna's mother supposedly recovered from her breakdown, she and Donna's maternal grandmother went to court and regained custody of the children. Donna thinks that her mother did not really want the children back, but that her grandmother had pressured her to sue for custody in order to retain her alimony and child support payments, her only sources of income. Donna, still visibly angry today about being sent back to her mother, says her father later told her that her mother's lawyer had put a social worker on the stand (who had never visited the home) who testified that he knew the family well and that Donna's mother was a completely fit parent. The lawyer downplayed her schizophrenia as a temporary breakdown from which she was fully recovered. Donna's maternal grandmother then moved Donna and her siblings into the cramped apartment over her garage where her mother had been staying. It was a rude awakening to Donna when her mother remained as psychotic as before and all of the parenting duties fell right back onto her. Her maternal grandmother made it clear that she had no intention of becoming the substitute mother as she stayed across the yard in her own house every night and locked the door against the intrusion of Donna and her siblings.

This change in living situation also severely decreased Donna and her siblings' access to their father. They were only allowed to see him on Sundays when he would take them to the park or out for ice cream, but he was no longer a parent to them in any daily sense. He remarried, but as Donna and her siblings were not allowed to have overnights at his house, she was never able to develop any strong connection to her stepmother. Nevertheless, even at a distance, her father remained an important figure to her. He was always available at the crucial transitions in her life to provide her with support.

Extended relatives such as aunts, uncles and cousins were in half the cases a significant source of support to the participants, but in the other half their support was almost non-existent. This resulted in a relatively low mean rating for them on the supports questionnaire (2.2 out of 5). Participants in the non-supported half noted that their mothers had isolated themselves from social contact with their extended families, (or in some cases, the relatives actively excluded their mothers due to their mothers' unpredictable behavior). Therefore, these participants as children had stopped having access to visiting or spending holidays with their extended relatives, furthering their isolation with their mothers.

Bonding with peers whose parents also had issues. Some participants felt most comfortable making friends with peers whose parents also had problems, such as mood disorders or issues with alcohol. While participants did not discuss their mother's illness explicitly with them, participants felt a bond with these peers over their shared experience of stigma regarding their parents' limited functioning. For example, Maya met a girl in the middle school marching band who was two years older than her who also played the flute and whose mother was bipolar. This girl began looking out for Maya as a protector and eventually became like the older sister she never had. They would visit each other's houses and practice their flute pieces together, although Maya never invited any other peers over. When Maya went to high school, she reconnected with this girl in the high school marching band and their friendship continued.

"Adopting" an alternate family and preference for male friends. Donna "adopted" her best friend's mother as her confidante and wondered why her own mother could never talk to her in the same friendly way. Similarly, when Karen was in high school, she was involved in student theatre and would attend theatre parties at the homes of other peers in the group. Through this she got to see other families interact emotionally with each other and realized the degree to which her mother's illness had hindered the emotional interaction in her family.

As a young girl, Holly gravitated to male friends saying that girls want you to confide in them about everything, but boys don't care about talking as much. They are more action oriented and just want to do things rather than talk. She says this is how she became "a tomboy" playing sports with boys. Karen also tended to have more friendships with boys than girls because she felt it would be harder to keep her mother's illness secret around girls.

Karen's best friend in high school was male and she got to know his parents well. She especially liked his mother who struck her as "so maternal" and they quickly created a bond together. His father was nice to her as well and she said that she got him too as "part of a package deal." She visited their home frequently and enjoyed that they treated her as an adopted daughter. The relationship lasted well beyond high school as when her mother was first hospitalized in her college years they brought meals to their home and were very supportive to her and to her father.

Attending college and grad school at the same university, Karen adopted the university as another loose alternate family where she “knew everybody” through her classes or her part-time job as an administrative assistant in one of the departments. She did not make a special bond with any particular person there, but said it was the university as a whole to which she felt very connected. Carol had a similar experience in the army. She felt that she knew and liked everyone as if they were family members, although she could not cite any particular person with whom she had a special relationship.

Adolescence: Escaping into one’s peer group. Adolescence normally entails shifting one’s focus away from the home and focusing more on one’s peer group. This was no different for the participants, except for their strict compartmentalization of their home life from their peers. Laura’s case illustrates this well. At the beginning of adolescence, Laura’s focus shifted from being immersed in her swim team and other structured activities to wanting to engage more socially with her peer group. She wanted to stop all the practices and meets and “just hang out” with the large group of peers who lived on her street. She describes this peer group as saving her life because it gave her a social structure and a role that she felt was completely lacking at home. It was almost as if there were no rules at home so she could leave the house at any time day or night and escape into “kid world,” as she called it. This group of peers also provided an alternate existence where she could escape thinking about her mother and family. She was one of the leaders and enjoyed the feeling of control she got from helping to run the group. She kept her life with her friends completely separate from her family life even though her peer group met right down the street.

Adult friends and sharing information about mother. Seven of the eight participants considered their friends and peer group to be one of the most important sources of their support (mean rating 4.4 out of 5 on the supports questionnaire). As an adult, Carol maintains a large network of friends as a critical source of support to her. Her roles in the group include leader, counselor and comedienne. She now feels free to discuss her mother's schizophrenia with many of her adult friends and she is pleased that they understand and continue to her accept her. Similarly, Steve has enjoyed bonding with many friends through his involvement in the arts and his witty sense of humor. Following his recent divorce, he entered therapy for the second time in his life and found it very helpful to see how his experience of his mother's illness continues to affect him in his adult relationships. With select friends he is now able to discuss his mother's illness. This will be discussed further in the Lasting Effects section.

In graduate school, Karen broke her pattern of having mainly male friends and joined a very close-knit group of women students. Interestingly, all of these women themselves have had a major medical issue or one of their relatives have had a mental health issue. She feels that their common experience of overcoming these types of adversity is what binds them together. She describes the support she gets from this group of women as "incredible" and she feels she "would do anything for them." They organize group made dinners for anyone in their network of friends who needs help or support. Karen loves that she finally feels fully part of a community that knows her and all of her issues and who accept her fully.

Caring for pets. A few participants discussed that they received comfort and affection from their pets growing up, but on the whole did not rate them as a major source of support (mean rating 1.87 out of 5). However, one participant, Carol, gave her pets her highest rating (5 out of 5). Carol's experience of being unable to trust either parent led her to believe that people in general could not be trusted. She only trusted her pets she said because, "They are non-judgmental." She surrounded herself with a menagerie of small animals including hamsters, gerbils, rats and even a red squirrel at one point. She feels that her pets were the main thing that saved her and she in turn has always been devoted to them. She proudly related that she once took a pet rat to the vet to get some tumors removed and the vet remarked that no one had ever bothered to treat a rat there before as they could buy a new one for a few dollars. But Carol stated solemnly that, "If you take on that animal, you make a commitment to it and you have to keep it." She feels that her learning trust through her pets later allowed her to learn to trust people, but this took her a lot of work.

Playing music/ bonding with mother through music. Karen and Maya both wrote in a choice of "playing music" as one of their greatest sources of support on their written questionnaire (Table 1). They discussed that playing music was a pleasure in itself, was a means of escape from the reality of the household, and was also a way for them to bond with others. Maya, who learned to play the flute from her mother in her more lucid periods, found that playing music together created an emotional connection between them that they could not achieve through conversation. Playing the flute then became the center of her social life as she joined the band clique at every level of school. For Karen, playing the piano daily was not only a means of escape from her mother's hyper-religious activities in the household, but a way she and her father, also a skilled pianist, created a bond with each other through their shared love of classical music.

Dealing with the Community: Secrecy versus Disclosure

All participants experienced the fear of stigma as children regarding their mother's schizophrenia, and initially kept their mother's illness a secret. Codes for "keeping mother's schizophrenia a secret" appear in Table 8. Codes included: *Always played at friends' houses (not my own), compartmentalizes home life /never invites friends home, does not invite mother to school events, experiences stigma from community (re: mother's appearance /behavior), fear of being found out/ being teased by peers, feeling shame re: mother's mental illness, family does not discuss mother's mental illness, family members only use euphemisms to refer to mother's schizophrenia, fears father's anger (if offspring speaks of /discloses mother's illness), fears mother will be locked up if illness is disclosed, fears siblings and self will be placed in foster care, has never discussed mother's illness with anyone (until interview), keeps mother's illness secret from peers, keeps mother's illness secret from teachers/ adults.*

Lack of acknowledgement and secrecy within the family. Seven of the eight participants experienced denial within their family that their mother had a mental illness. Their fathers and other relatives would generally avoid discussing it. If it needed to be mentioned it would be brought up tangentially, if at all. For example, Holly's relatives never said her mother was "mentally ill" or had "schizophrenia" but would instead only use euphemisms such as "she's troubled" or "she has some problems." Similarly, Steve's relatives referred to his mother's mental illness as "her breakdown" in a manner that suggested this was something in the past that was no longer current. Steve who lived with her was quite aware that she had never recovered following her first hospitalization and wondered why everyone was in such denial that she had schizophrenia and that it was chronic. Carol said that not just her relatives, but her mother too would refer to her "breakdown" as an event in the past that was over. Even after being off and on medication for almost twenty years now, her mother will still get angry and deny it vehemently if Carol refers to her as currently having a mental illness or as having schizophrenia.

This initial experience of stigma within the family seems to have led participants to believe that their mother's schizophrenia was something that should never be named or discussed. Most were never told explicitly by their father or any other relative to keep it a secret, yet they all got the unspoken message that it was not to be mentioned.

Keeping mother's schizophrenia secret from peers. All of the participants initially kept their mother's schizophrenia secret from everyone at school, including their best friends. For example, Steve explained how he gave his friends virtually no information about his family:

> I think I kept it (my mother's schizophrenia) a secret all through most of school. Most people at school didn't know that my mother was mentally ill. In fact, I distinctly remember that my parents had been divorced for seven years and I remember one of my friends coming and telling me that another friend of ours had just told him that my parents were divorced as if it was some kind of revelation. And I mean, my mother had been mentally ill already and that was a way bigger secret and the fact that some of my friends didn't even know my parents were divorced only goes to show how much I kept it hidden. Certainly, I wouldn't tell people and I wouldn't invite friends over. It (my mother's schizophrenia) was pretty shameful…it was so impossible to explain my mother's illness and even our lifestyle. That's why I hid it from people… I lived ten miles from my school… so none of my friends lived nearby. So, it was easy for me to keep my friends away. I just went to them…

Steve maintained utter secrecy about himself because of his powerful, underlying feelings of shame. This sense of shame due to stigma regarding their mother's illness was common to all participants.

Inadvertent disclosure. Maya's case was unusual in that her mother's erratic behavior in public could not go unnoticed in the small town where they lived. It was clear that she was mentally ill as she would have frequent angry outbursts in public where she would scream and flail her arms. An unfortunate consequence of Maya's enmeshed relationship with her mother was that after Maya went to live with her father when she was in the fifth grade, her mother had great separation issues with her. Despite Maya's father's house being right across the street from her mother's affording her ample opportunity to have contact with Maya, her mother would show up at her school and make loud scenes trying to see her. The school was locked down on one occasion when her mother kept trying to force her way into the building. Another day, she showed up yelling loudly at the practice field where Maya's marching band practices were taking place. This caused everyone in the band to become aware that her mother was mentally ill. After some initial teasing from a few peers that day, everyone in the band became supportive and refrained from teasing her. Maya thinks the band director, with whom she later formed a close relationship, had met with the group separately and set expectations for the group's behavior toward her. Being accepted by the band members allowed her to feel she had found the social niche where she belonged. She went on to play the flute in her high school and college marching bands and orchestras and made a number of friends for life through these groups.

Disclosing mother's schizophrenia to peers. Codes for participants disclosing their mother's schizophrenia appear in Table 9. Codes included: *Bonds with friends whose parents also had issues (MH/ alcohol), discloses mother's schizophrenia to best friend, discloses mother's schizophrenia to coach/ activity advisor, discloses mother's schizophrenia to partner/spouse, discloses mother's schizophrenia to teacher/coach/ activity advisor, discusses mother's schizophrenia with therapist (as adult), mother inadvertently discloses illness to community through odd behavior,* and *talks about mother's schizophrenia freely (as adult).*

None of the participants intentionally disclosed their mother's schizophrenia to any peers while they were in elementary or middle school due to fears of stigma. (In Maya's case it was inadvertently disclosed by her mother's behavior). Things changed for some in high school. For example, Carol when she was about fourteen began to make vague disclosures to her groups of friends. When her girlfriends would talk about how their mothers were "cows" or were "crazy," Carol would join in agreement saying, "Oh yeah, my mom's a cow, too," or "My mom's crazy too," although she would not explain that her mother actually had a mental illness. At eighteen, she experimented with disclosing it to a boyfriend but it had a negative outcome (discussed further in the dating and intimacy section below).

Donna made a best friend in high school and was able to fully disclose her mother's schizophrenia to her and to her friend's mother as well. They were understanding and supportive and made her feel welcome at their home anytime she needed to get away from hers. This friend also aided her in launching from the home as the friend attracted Donna to the idea of going away to nursing school together.

For some participants, it was not until they were adults that they were able to discuss their mother's schizophrenia openly with friends and partners. Reflective of the enduring power of stigma, two participants reported that they had never spoken about their mothers' schizophrenia to anyone in any detail until they were interviewed for this study.

Disclosing mother's schizophrenia to adults at school. Participants on the whole appear to have kept a comfortable emotional distance between themselves and the adults at school. Accordingly, teachers, coaches and activity advisors received relatively low ratings on the sources of support questionnaire (mean ratings: teacher 2.2 out of 5; coach/activity advisor 1.8 out of 5). But in cases where participants did confide in these school figures, they often found them to be invaluable sources of support. Four of the eight participants, at one time or another, confided in either a teacher, coach or activity advisor about their mother's mental illness. For example, Steve whose mother was first hospitalized when he was sixteen was able to confide in one of his high school teachers. With her help, he let his other teachers know about his mother's mental illness and he felt supported by them as a group. While Holly and Laura never confided in their teachers, Holly was able to confide to her cross country coach and Laura to her swimming coach, and both found them sensitive and supportive to them. In contrast, Karen, despite being an honor student and playing three different sports, never confided about her mother's mental illness to any of her teachers or coaches. She said that some of them may have noticed how socially withdrawn her mother was when she attended her games, but she cannot recall anyone inquiring about her mother's mental health. She noted that social conventions would have made too awkward for them to inquire.

Little contact with school counselors /child therapists. School counselors /child therapists received relatively low lifetime ratings (mean rating of 1.8 out of 5) as sources of support. Seven of the eight participants never received any school counseling or therapy as children. This is significant as one would assume that school counselors would be front line adults to whom the children would turn to (or be referred to by teachers) when they needed help. However, this was generally not the case. As adults, participants felt that their not having had therapy as children was a lost opportunity. Several said that if someone in authority had told them to go to therapy, they would have gone, but they would have never sought it out on their own. They felt that therapy would have helped them to understand their mother's mental illness, and to recognize and work through their own emotional reactions to the changes in their mothers.

Participants would not necessarily have wanted to use their therapist or counselor to get services for their mothers. Some participants reported they had feared that if they brought attention to their mother's illness that she would be taken away and locked up in a mental hospital. They also feared that they and their siblings would then be split up and placed in foster care. Thus, their fear of being separated from their mothers and/or siblings was the primary factor that prevented them from seeking out counseling or therapy at school.

In contrast, Maya, the one participant to ever attend any form of therapy as a child, attended private individual therapy away from school for several years and rated her therapist highly as a source of her support (5.0 rating). She emphasized that the therapist had her father participate in some sessions and she found that his supportive presence was important in her treatment. His agreement with her therapist that her mother's illness was not her fault was crucial in freeing her from feeling responsible for causing her mother's schizophrenia.

Launching: Separating from Mother

Leaving home for the first time. The majority of participants reported that a major turning point in their lives was leaving their homes and their mothers for the first time. For most, the need to leave felt urgent.

Codes for leaving home for the first time appear in Table 10. They included: *becomes anxious/depressed after leaving home, escaping into college social life /avoiding contact with mother /family, feeling confident/ maintaining a "can do" attitude, feeling manipulated by mother (to return home), feeling an overwhelming need to escape the home, feeling obligated to return home to help mother/siblings, feeling separation anxiety/ homesickness, feeling survivor guilt (re: leaving siblings, mother behind), making a conscious decision to leave, returning home/ responding to pull to "save" mother, taking advantage of opportunities, worries about mother* and *worries about siblings.*

Feeling an overwhelming need to escape the home, making a conscious decision to leave. Holly went away to a small, liberal arts college several hours from her home. Being the oldest who had managed the home, she felt some tension about leaving her younger siblings behind with her mother, but reassured herself that they would be alright. Her father was still in the home and her grandmother and aunt who lived nearby would continue to check in on them. She tried not to think about leaving them because she said emphatically, "I just needed to go. I had to get out." The constant tension around her mother and the pressure on her as the oldest was so great, she felt like she had no option but to leave.

Similarly, Steve was so determined to leave home, he left nothing to chance. He told an anecdote of when he was applying to university in England, he put down his father (whom he didn't live with) as his emergency contact and not his mother (who got quite upset when she saw this). While a seemingly minor matter, he feels it reflects his desperation to "escape" from living with his mother:

> …I think I was aware that my mother was about to head for another breakdown She wasn't the most reliable person for anyone to contact. And I certainly didn't want her jeopardizing my escape from that situation (of living with her). God, you know, I wanted to get out of there (laughing)! I didn't want to risk anything…

Carol was so eager to get away from home that she joined the British Army at age sixteen and was sent to Northern Ireland. She explained only half-facetiously that "dealing with terrorists was preferable to dealing with (her) mother."

Feeling confident/ maintaining a "can do" attitude; taking advantage of opportunities. Donna exemplified participants' drive to launch from the home and succeed despite difficult circumstances. Despite being thrust into the parenting role with her four younger siblings, she always maintained what she termed a "can do" attitude, and took advantage of opportunities to achieve her goals of leaving the home, being able to make her own living and starting her own family. She explained:

> I wanted to be a mother. I wanted to leave home. And I did it. And I wanted a telephone and I got an Avon job and I did it at 14-years-old. And I worked and got money and went to nursing school as the most prepared. I had towels and soap and gum bands and band aids and people used to come and buy things off me. I was (like) a store.

Donna demonstrated her ability to make her own opportunities when she interviewed for nursing school. She was required to bring her mother to the interview and surprisingly her mother was able to "act normal" for the duration of the meeting. Donna told the interviewer point blank (against her mother's protests) that the family was on welfare and that if she was going to attend their nursing program that they would have to pay her tuition plus expenses. The interviewer liked her assertiveness and offered her a full scholarship plus stipend on the spot. This paved the way for her nursing career, although there were other obstacles.

Feeling survivor guilt re: leaving siblings, mother. The need to leave was complicated, however, as participants simultaneously felt a strong pull to remain to help their mothers and/or younger siblings. After they left, they often felt a form of survivor guilt regarding those they left behind. They described their inner conflict as, "How can I be off and having fun when my mother and siblings are so miserable?" This was particularly true of the participants who had been in a parentified role in the family.

Feeling separation anxiety/ homesickness; worrying about mother/family members. Several participants reported having significant emotional difficulty due to homesickness /separation issues shortly after they first moved away. For example, Karen went to a college out of state at eighteen but felt the first year was "a disaster," due to her being homesick. She had been constantly worried about whether her mother was alright and whether her father was left with too big of a burden caring for her alone. She left school mid-year to return home and transferred to a local college the next fall. She moved into the dorms there successfully, her separation anxiety no longer an issue as she could easily return home to see her parents whenever she felt the need.

Becoming anxious/depressed after leaving home; feeling obligated to return home to help mother. Donna went to live in the dorms at nursing school at eighteen but became so anxious and depressed that her best friend from high school who was also living in the dorm said she “expected to find (her) hanging from the pipes.” College officials then intervened and had the school doctor put her on medication. Her anxiety about being away from home was exacerbated when she learned that her mother had no heat in the home and her younger siblings were living in their coats. Her mother was refusing to leave the frigid apartment because of her own separation issues with Donna’s grandmother who lived next door. Donna then dropped everything to try to find them a new apartment with heat. She succeeded, but her mother still refused to move due to her need to have Donna’s grandmother nearby. Donna then arranged for the heat to be fixed at their old apartment and paid the bill out of her own pocket. Only then that she was able to settle back into her studies. However, in her spring semester, she was taking psychiatric nursing and was assigned to work with a woman with schizophrenia and she had such a visceral aversion to being around the woman, that she almost dropped the class. But, she persevered and was much relieved when the course ended and she had passed.

Escaping into college social life /avoiding contact with mother /family; feeling manipulated by mother (to return home). Like Donna, Steve’s escaping to live away from home did not necessarily mean that he was free from issues arising from his mothers’ schizophrenia. During his first year at University, he was so excited to be away from home that for the most part he was able to just not think about his mother. He spent his time socializing, going to dance parties and getting into what he called “general mischief,” such as the time he tied a bed sheet to his skateboard and “windsurfed” across campus. However, in his second year, after he heard that his sister had developed anorexia, his worrying about her, his mother and the family caught up with him and his grades began to suffer. He finally went to his don and explained to him that his mother was mentally ill and that he continually needed to disrupt his studies to travel home to check on her. He found sharing this confidence a very positive experience:

> I learned that you could talk to other people (and) that other people would listen and understand, that what was happening to me wasn't something incomprehensible to anyone else… When I heard my sister was anorexic, I did go to a counselor (at the University) …but, I also would talk to my don…I would tell him what was going on at home. I didn't hide it. And it saved me from being kicked out of University…my grades were dreadful at times and I would never know if my mother was really on the verge of being about to head back into hospital or whether she was just acting crazy, or just trying to pull my emotional strings so that I would visit. So, I was constantly having to go back home, find out what was going on, and of course the second I got back (home) the crisis would have abated and there wouldn't be a crisis anymore…(This was going on) the whole time I was in University. I think I found it easier in the first year at University to hide from it and just ignore it all. But, through the rest of the time there, it just got harder and harder.

Despite these struggles, Steve was able to graduate with a degree in mathematics and a minor in modern dance. He was so good at dance, in fact, that he was able to audition for professional companies. As going away to University had not allowed him to leave his mother and her mental illness behind, he now resolved to leave England altogether and joined a dance company in New York City. He continued to feel guilty about leaving his mother and sisters behind, but he said he just needed to go pursue his own life and dreams. He related his experience to that of the boy projectionist who leaves his mother and small town to become a film director in the movie, Cinema Paradiso:

> There's a moment in the movie when the director returns to his mother having been away for twenty years and made his career as a movie director. And she says to him, "Oh, I understand why you left and didn't come back." And it just devastates me every time I think about it. And that's how I feel…I feel the parallel that I *had* to leave in order to live my life. I feel that I too am an artist and that I have to be in the world in order to be an artist and I can't be the caregiver to my mother and be that person that I feel I really am…I identify with him of

> course, but I suppose I identify with her in that, that is what I would want to give to myself, or that is what I would want someone to give to me, is permission to be myself in the world and not to feel guilty that I have left the child in the black hole [reference to earlier comment he made about a novel where a child is left alone in a black hole to serve as the scapegoat who pays for all the sins of the world] … I feel guilty and helpless at the same time…every now and again I'll see the phone there, but that feels like such an empty experience (to call her)… [Interviewer: Do you feel responsible for her situation?] I feel there is more I could do, but I also feel that whatever I do would not really change anything. It would not necessarily make her feel happier, it would only make me feel that I made her situation better, but I wouldn't really be changing her situation…

Returning home: Responding to pull to "save" mother. Despite their burning need to leave home and get away from their mothers, several found themselves returning home within a few years to live with their mother again. This was true for Carol whose story illustrates the constant pull that many offspring experience to try "to save" their mother. Carol returned home at eighteen when her army service was up, a decision she soon came to regret. She discovered that her parents had all new furniture and that they had charged it all in her name while she was away. They had not been making any payments and her credit was ruined. She then had to convince the bank that these purchases were the result of fraud committed against her and she returned all of the furniture. Shortly after this, the incident took place (described earlier in the "Walking on eggshells" section) in which Carol and her mother both tried to stab each other and her parents moved out, leaving Carol and her brother alone in the empty house.

Carol then met her husband when she was nineteen. They married within a few months of meeting and decided to immigrate to America. After about six years in the U.S. working various odd jobs, attending support groups for family members of the mentally ill, and volunteering with adults with schizophrenia, Carol felt ready to go home, hoping again to rehabilitate or "save" her mother. She and her husband tried living with her parents for the first three months and it was terrible for them. Nothing had changed since Carol had left except her father was now addicted to prescription medication. Her mother had been hospitalized once and took medication briefly, but due to the side effects, she had stopped again. Her behavior was as bad as Carol remembered from childhood and she was refusing to restart taking her medication.

Carol and her husband bought a house nearby and Carol kept trying to “fix” her mother and her family. But, after a few years she became tired of being around her family’s craziness again constantly. She felt badly for her younger sister, because she had failed to ever launch from the family. She had no job and had never been involved in a serious love relationship. Sadly, Carol realized she was never going to be able to cure her mother or her dysfunctional family. She and her husband then sold their house and moved back to the U.S. for good. She had, however, come to an acceptance of the permanence of her mother’s schizophrenia. She felt she had done her best to help her mother and now felt that it was no longer up to her to fix it. She sublimated her urge to be a caretaker by getting a master’s degree in Psychology and at the time of her interview was running therapy groups for adults with serious mental illnesses.

Lasting Effects: Impact of Mothers’ Schizophrenia on the Adult Lives of Offspring

Psychological status of offspring and seeking therapy. Information in this section comes from the demographic questionnaire and from interview question 31. All of the offspring participants were mentally healthy adults who had never been diagnosed with any major mental illness. Only one of the eight had ever received therapy as a child, although all seven others said it would have been helpful to them in understanding their mothers’ schizophrenia and their own feelings. Six of the eight first received individual therapy as adults and the average age at which they first sought treatment was 26.6 years with a standard deviation of 6.7 years and a range of ages 20-39. Participants on average rated their adult individual therapy as ‘very helpful’ (mean rating 4.1 out of 5). They rated the frequency that their therapy addressed the issue of their mother’s schizophrenia as 2.6 out of 5. This broke down to three participants who gave a rating of 4 that the issue was addressed ‘often” and three participants who gave a rating of 2 that it was seldom addressed. One participant gave it a rating of 0, that it was never addressed. This breakdown reflects that when offspring have sought individual therapy, that only approximately half the time have their therapists given a high priority to the issue of their having been raised by a mother with a severe mental illness.

While three participants reported a significant period(s) of feeling depressed in their lives, only one participant ever required medication for depression. Four participants reported issues with anxiety that led them to seek therapy and only one required medication. Three of the eight participants had attended marital therapy, and two of these three marriages had ended in divorce. The individual who had marital counseling where the marriage remained intact had also participated in group counseling, family counseling and a Twelve Step program (Overeaters Anonymous). None of the participants reported that they have ever had any issues with alcohol or substance abuse.

Only two of the eight participants reported issues of alcohol or substance abuse in their spouse/partner. In one case, the spouse’s abuse of alcohol and substances directly led to their divorce. In the other case, the participant confronted her husband and he was successfully treated. They have remained married and he had been sober for over twenty years at the time of her interview.

Dating and intimacy. Codes for "What have romantic relationships been like for you (question 23)?" appear in Table 11. Codes included: *attractive to others/ no trouble getting dates, avoids expressing anger/discontent to partner (fears being seen as "crazy"), casual dating is easy, dating is a "fun" escape, difficulty expressing feelings to partner/ feels like "learning a new language," does not bring dates home /arranges to meet dates away from the home, dumped after boyfriend hears story of mother's illness, expects partner to "magically know" what he/she wants (without being told), feeling controlled in marriage/relationship, held anger causes loss of libido (in marriage), keeps mother's illness secret from dates/ partner, lack of emotional intimacy leads to divorce, lack of healthy parental role models for intimacy, marries quickly after dating for only brief period, mother makes delusional accusations re: dating to offspring, not interested in dating (due to issues with autonomy), passive in relationships /does everything partner's way, serious dating feels more difficult, troubles with emotional intimacy,* and *trusting partner is initially difficult /learns to trust but is a long process.*

The majority of participants reported that they had little difficulty attracting suitors or finding dates as teenagers and young adults. Participants typically felt anxiety regarding stigma at the start of relationships and would try to hide the fact of their mothers' mental illness from their boyfriends or girlfriends.

Stigma impacts dating relationships: Keeping mother's illness secret from dates. Several participants discussed that adding to the typical teenage anxiety about whether their date will like them, they had to worry about how the date might react if they somehow disclosed their mother's mental illness. This added a layer of anxiety to their dating relationships. For example, as a teenager, Carol never brought any of her dates home to meet her parents, but would ask them to meet her away from the house. However, once when Carol was about eighteen, she decided to test her fears by inviting home a young man she had just begun dating to see how he would react to her family situation. At the time, Carol and her brother were living alone in the house (after her parents had moved out), with no furniture because it had been repossessed. She explained to the boyfriend that her mother had a mentally illness and that her father had taken her to live elsewhere. The boyfriend seemed disturbed at hearing this and after offering an excuse abruptly left and never phoned her again. As he failed her test, she felt this confirmed her fear that stigma would prevent anyone from ever getting involved with her. Although, happily this proved not to be the case as will be discussed below.

Casual dating is easy, “Learning a new language.” Other participants focused more on the enjoyable aspects of their early dating experiences. Going out on dates was fun and felt like a wonderful escape from their families at home. However, as their dating developed into steady love relationships, several discovered they had issues with emotional communication. Most participants felt that these issues were significantly related to their lack of experience of sharing emotional communication with their mothers post -illness. Participants understood that there are many factors involved in how a person learns to relate to other people. But in the words of one participant, getting involved with a romantic partner and learning to share their feelings often felt like “learning a new language.” Some participants had experience of sharing emotional communications through their fathers, siblings and/or friends, but they still felt that the lack of emotional exchange with their mothers post-illness continued to affect their ability to recognize and share their feelings with others.

Difficulty with trust and emotional intimacy. Steve described how he and both his sisters have always had difficulty with trust in their adult love relationships. At the time of his interview, both of his sisters were in their mid to late thirties and had never married. He felt it was notable that his middle sister would often refer to each of her boyfriends as, "the guy I'm seeing right now" as if she had no intention of allowing any relationship to get too serious. Steve believes that his mother's schizophrenia has influenced both his and his sisters' ability to be intimate with others, but he feels this is not the sole factor involved:

> I think all of us are pretty afraid of intimacy. There's a certain point at which we feel uncomfortable. So, yeah, that would affect who we choose as a partner. But, I think there's so many other (factors). To say that it's directly related to my mother being schizophrenic or is it more the fact that my mother being ill only accentuates the way that they (my sisters) played out relationships in their childhood…Also their relationships with my father, I think, would be much more—whatever—seminal (laughs at the pun) to their relationships with their boyfriends.

But, at least for Steve, his relationship with his mother would seem to be the biggest factor influencing his later romantic behavior. He described how as the oldest male child even in his extended family, he had always been "the golden boy" in his mother's eyes who could do no wrong. After Steve's parents divorced when he was eleven, he feels that in some senses his mother encouraged him to become "the man of the house," and he eventually became emotionally spousified by her. He described how his role shifted with his sisters so that he took on part of the paternal role toward them (although they still saw their father every Sunday for his visitation day).

When he and his two younger sisters were teenagers, his mother and his middle sister were constantly getting into angry screaming matches with each other that would often turn violent. They would hit each other, throw dishes and sometimes even break furniture. He and his youngest sister dealt with it at the time by finding the comedy in the intensity of their fights. But, being somewhat traumatized by witnessing this, when Steve began dating he found that he consciously avoided making any expressions of anger or statements of discontent to his partners. He could not even bring himself to make simple requests. He was afraid that if he seemed too demanding or expressed any negative feelings that his partners might think he was “crazy.” He has been married twice and at the time of his interview, had just recently separated from his second wife of seven years. He found that his being unable to express any anger or disagreement had led to everything being done his wife’s way. This caused him to feel overly controlled by her. Through individual therapy after separating from her, he came to understand that he had never communicated his feelings or what he wanted to either wife, but expected them to “magically know” his feelings and wishes. His held anger had caused him to not want to be physically intimate with them. He had enjoyed the friendship parts of the relationships and had felt that this was enough for him. His reluctance to be physically intimate with them, he feels, was the major factor that led to the demise of both marriages.

Not interested in dating due to enmeshment with mother/ issues with autonomy. Robin, who was forty at the time of the interview, reported that she has had difficulty with trusting others resulting in her only having been involved in one serious and two brief relationships in her life. The one serious relationship lasted two years, but ended because her being enmeshed with her mother caused conflict with her boyfriend. Anytime her mother called her, Robin would drop whatever she was doing with her boyfriend and run right home. When the boyfriend complained that she had two older sisters who could share in the caretaking of her mother, Robin told him bluntly the job was solely hers. Their conflict over this issue eventually led them to break-up. Even after her mother died when Robin was twenty-eight, she never got seriously involved with anyone else because she said she could never share enough of herself. She was too afraid of losing her independence. At the time of her interview, she did not have a partner and said she is not particularly interested in dating. When asked if her mother's illness had affected her ability to enter into love relationships, she responded:

> Oh, big time, because I don't trust! Why would I allow you into my life, where everyone in my life has let me down? So, I'm going to let you into my life as a major partner…just so I can say, 'Honey, go pick up bread' and you come back with no bread? That would piss me off. So, I would rather go and get my own bread and just not deal with the romance aspect of my life…

Lack of healthy parental role models for emotional intimacy. Holly crystallized a theme alluded to by several other participants when she commented on her lack of healthy parental role models for emotional intimacy. Because the emotional connection between her parents had been lacking due to her mother's illness, she had never seen them hug, hold hands, kiss or express affection to each other in any way. This lack of a parental model of emotional intimacy made it difficult for her to know what a healthy relationship looked like. This left her unable to recognize the abusive tendencies of the man who became her second husband (described above).

While Karen's parents had been affectionate with each other when she was young, after her mother became ill when she was nine, she rarely saw them interact affectionately. She thus felt fascinated on the occasions when she had the opportunity to observe her friends' parents interacting in a positive emotional manner with each other.

Despite the lack of healthy parental models, some participants seem to have brought their resilient qualities to bear and have had successful love relationships. After leaving nursing school and getting her own apartment, Donna met and fell in love with her landlady's son. They bonded over the fact that both of them had mothers with mental illnesses (her husband's mother was either bipolar or had schizophrenia after having been a child survivor of a Nazi concentration camp). They were married within a few months of meeting and went on to raise three mentally healthy, successful children. While acknowledging they have had their ups and downs, Donna feels they have been happily married for 36 years.

Carol feels that she got into some bad relationships at first because she "didn't value (herself) enough." Then, she said simply, "I got lucky and met my husband" through mutual friends. They were friends for a month or two before they dated. She found him "so laid back" and non-controlling (unlike her father) and because she "felt like (she) could …totally be (herself)" around him, she knew within two weeks of dating that he was the man she wanted to marry. When she told him about her mother's schizophrenia, he "didn't bat an eye" and told her he loved her no matter what and they were married soon after she turned nineteen. At the time of the interview, they had been happily married for 24 years. She described her husband as her best friend, saying "We talk. We *really* talk to each other. And we laugh together all the time."

Early first marriage. This data is taken from the written questionnaire. Five of the eight participants, four females and one male, had been married (three subsequently divorced). The median age for the four women at the time of their first marriage was 21.0 years (and the one male was age 25 when he first married). The median age reflects an early age of marriage compared to the general population of the United States. The median age for first marriage in the U.S. in 2001 was 25.0 years for females and 26.0 years for males, according to the UN Economic Commission for Europe, Trends in Europe and North America (2001). Data from the 2002 National Survey of Family Growth Probability based on analysis using life table methodology that calculates how likely it is that an individual will marry by each age, showed that the probable median age for marriage in the U.S. was 24.8 years for females and 27.3 years for males in 2002. This study also showed a clear trend that the average age of marriage has increased significantly for females and marginally for males in the 1990's and the 2000 decade (i.e. people are getting married at an older age). This trend makes the effect of the results here even larger as most of the participants were married in these same decades. A limitation of this study is its small sample size. This data would have to be replicated in a larger study to validate the results. Possible reasons for early marriage in offspring of mothers with schizophrenia will be discussed in the next chapter.

Spouses as sources of support. All four of the participants who had a current spouse or partner considered them to be an important source of their support (mean rating 4.3 out of 5). Also, one of the divorced participants felt that his ex-wife continued to be a good support for him post-divorce. Carol described how she had never been able to trust anyone she dated until she met her husband at a party through mutual friends. She liked how easy he was to talk with and that he was so “laid back” (in contrast to her father who had been very controlling). They went out with a group as friends for a month before they dated, but she knew after two weeks he was the man she wanted to marry. The first year or two of the marriage was rough she feels because she still had trust issues. But then, when she experienced how he was there for her no matter what and not trying to control her, that she learned to be more relaxed with him. After 24 years together she still describes her husband as her best friend. Similarly, Karen described feeling “blessed” to have her fiancé, whom she had been dating for three years, as he is fully aware of her mother’s illness and accepts Karen unconditionally.

However, not all spousal relationships went well. Holly’s first husband had a daughter from a prior relationship and he and Holly went on to have four more children together. They got along well at first, but over time his workaholic tendencies and her tendency to “micromanage everything,” as she put it, led to chronic marital conflicts. Her husband then began drinking and became involved with heavy drug use. Tragically, his falling asleep while under the influence when he was supposed to be watching the children in the pool, led to the drowning deaths of Holly’s stepdaughter and oldest daughter. Their marriage was unable to survive the loss and they divorced.

Holly then entered what she termed a “rebound relationship” with another man, although she ended up marrying him after only a few months. After they married, she discovered that he had concealed a criminal past of physical assaults against women. He then became physically abusive to her. The last beating he gave her resulted in Holly having a broken jaw and some permanent hearing loss, an offense for which he is still incarcerated. Through individual and group counseling, Holly has been able to recover her sense of stability, although she said, “You never fully get over the death of your child.” She continues to parent her three younger children from her first marriage successfully while going to school and working part-time.

Reluctance to have children of their own. Only two of the eight participants were parents with children of their own. They both rated their children as extremely important (5 out of 5 rating) on the Sources of Support questionnaire. One participant had three biological children and the other had four biological children (and one step-child). This yielded a total of seven biological children born to the eight participants. Thus, the birth rate of the participants as a whole was less than one child (0.9) per participant. This rate was a significant 68% lower than their mothers' overall birthrate of 2.8 children per mother.

Six of the eight participants did not have children of their own by choice. Three of these six participants had been married for at least seven years and reported that their not having children was an active choice. All six endorsed at least mild fear that if they had a child, their child might develop schizophrenia. This fear was an important factor in their decision to remain childless. A few also feared that they themselves might develop schizophrenia later in life and felt that they would never want to put their child through what they went through as children in dealing with their mentally ill mothers.

One of the participants who was divorced but involved in a new relationship stated that she would possibly be open to adopting a child in the future, but that she did not want a biological child out of fear that the child might develop schizophrenia. The three participants who were single/ never married all reported that they did not think they wanted children in the future. One mentioned only her fear that her child might develop schizophrenia and said she could not go through that again. The second of these women who takes great pleasure in her job working with children, said she felt that having a child at home as well would be overwhelming. The third who has been dating her fiancé for three years said with surprising bluntness, given her overall caring and outgoing nature:

> I've really never met a child I like. I know that sounds terrible, but I never have… maybe my (fiancé's) nephew is the one child that I've felt maybe I could do this (be a parent) around. But in general, I just think there is too much pain in the world to bring a child into it.

One of the participants with children also had a grandchild through her son for whom she had been the primary caretaker for three years. She found this as fulfilling as she had found raising her own three children. Interestingly though, her two adult daughters have both told her that they have no desire to ever have children of their own, suggesting that the effect of having a mother with schizophrenia on the child-bearing practices of offspring may possibly extend beyond one generation.

The fear of schizophrenia developing in their child or in themselves was not the only reason participants cited for remaining childless. For Carol, the more significant factor in her decision to not have children stemmed from her having been a parentified child. She and her husband reached this decision despite their being stably married for twenty-four years with an ample dual income. Carol also described that she gets along quite well with other people's children. She had a mild fear that a child of hers would be at greater risk to develop schizophrenia, but of greater concern is that she has had enough of parenting as she was forced since early childhood to help raise her two younger siblings. She now wants to live her adult life unencumbered by parenting children and channels her maternal urges into caring for her pets.

Doing things for others /entering caregiving professions. "Doing things for others" on the Sources of Support questionnaire (Table 1) received the second highest score (mean rating 4.4 out of 5). The majority of the participants discussed that they have always had a strong desire to do something tangible with their lives, often something that also benefits other people. For example, Holly, a paralegal and business student, volunteers through her church at a food bank several days per week.

Five of the eight participants were currently working in, training for or retired from care-giving professions. Donna was a registered nurse for many years before retiring on medical disability. Robin was a mainstream preschool teacher before shifting into doing behavioral therapy with children with autism. Carol, after leaving the army, had a series of jobs including shopkeeper and hairdresser. She then went back to school for a master’s degree in psychology and works at a psychiatric center conducting group therapy with adults with severe mental illnesses. Laura has a Ph.D. in Clinical Psychology and works at a hospital doing evaluations of children with developmental disabilities. Maya was a volunteer teacher in Americorp before entering graduate school for social work.

The predominance of care-giving professionals may in part be a consequence of recruitment for the study, as flyers were posted at a psychiatric institute where they were seen by professionals in the field of psychology and by members of support groups. Nevertheless, only three participants were recruited through the flyer posting there. Five others were recruited by other methods: two through an internet posting to the general public and three by word of mouth. The effect size of this seeming trend may be exaggerated due to the recruitment method. A survey with a larger sample recruited from the general public would be needed to evaluate its validity.

Several participants described that their experience of their mother's having schizophrenia led them to pursue a career in the field of psychology, as for example, Carol described:

> I work right now… with people who have severe mental health disorders and one of the main reasons I'm in that field is because of my mother. I wanted to find out more about schizophrenia and things like that so it kind of led me down that path…

Laura with a Ph.D. in Clinical Psychology said simply, "What led me to it (psychology)? I'm sure it had something to do with my upbringing…" although she did not elaborate. For Maya, curiosity about her mother's schizophrenia and her wish to understand it influenced her choice of majoring in psychology as an undergraduate and of later pursuing a master's degree in social work:

> …In high school I loved psychology,(but) I kind of overlooked it. (When I got to college,) I was like no I'm going to go the bio/pre-med route. But, I always found just talking about human behavior and the brain…really fascinating considering that I'd been dealing with (my) mom on a day to day basis when I was a kid. So, I felt like it was something that I could really relate to and I had that drive to want to learn why and what's going on, what causes this or that (in terms of mental illnesses)…

Robin was attracted to her job as a behavioral therapist with children with autism because it was a good match for her need to feel some control over her environment:

> … I think with autism it's just being able to see the issue, unlike my mom where I couldn't control the issue. But, with autism I could see the issue and figure out how to tweak it best, so that I can get the best learning out of these kids…they hooked me because they keep me motivated, they keep me thinking and every time I see a behavior, I think 'how can I change that behavior to what I want it to be?' So, it's a very controlled and systematic (approach) and I think that's what led me to it…I needed that very systematic, controlled part of my life… I thrive off that.

Further reasons for participants' preference for entering care-giving professions will be discussed in the next chapter.

Pursuing talents/ entering the arts. Two participants were able to develop their talents and enter the arts as their initial careers. Their being raised by a mother with schizophrenia had no apparent ill effect upon their ability to train for and enter the arts. Karen had the ability to accomplish things in several fields. She was such a talented classical pianist coming out of high school that she considered applying to Juilliard in the hopes of playing professionally. However, she had also enjoyed acting in student theatre, so she instead chose to study theatre in college. After getting her degree in acting, she moved to Chicago to try to act in professional theatre there. Like most new actors, she found that paying roles were hard to come by. So, instead she landed some modeling work and transitioned to working back stage as a production assistant and dresser at a top theatre. She later picked up work as a free lance editor for a book publisher and her enjoyment of this experience led her to return to school for a master's degree in English Literature. In every endeavor, her upbeat personality attracted valuable mentors who inspired her and helped her to find new opportunities. She believes that dealing with her mother's illness taught her flexibility and made her somewhat fearless in trying new things.

Steve possesses a similar range of talents. While earning a degree in mathematics, he also minored in modern dance. When he graduated, he moved to New York City to become a professional dancer, performing in a company for several years until a knee injury forced him to retire. He then started a new career as a performance artist combining silent drama and dance movements with electronic media. He was also a sought after music disc jockey in the underground arts scene of New York. He was able to support himself in his artistic endeavors by using his math and engineering background to work as a set designer and lead carpenter for professional theatres.

Sources of Resilience

Participants were asked in question 28, “At times when life feels difficult, describe what sustains you, i.e. a relationship(s), religious beliefs, a philosophy, and attitude, etc. or what combination of things?” Codes for this appear in Table 9 and include: *acceptance of life’s highs and lows, being with friends/ talking with friends, belief in God /Higher Power, breaking cycle of self-blame /controlling negative thoughts, keeping a positive attitude, keeping a sense of humor, logical thinking /reasoning with self, participation in formal religion, philosophy that life is just, spiritual relationship with God (apart from formal religion), striving for balance (in life),* and *taking care of (my own) children/ grandchildren.*

This question attempted to get more at the philosophical stance and internal thinking of participants to look at their sources of resilience. One of the more notable effects of having a mother with schizophrenia, and one that was not anticipated by the interviewer, was that the majority said they avoid formal religion as a direct consequence of their mother’s mental illness. Participants also rated their belief in a Higher Power on the sources of support questionnaire.

Belief in a Higher Power, but avoidance of formal religion**.** All eight of the participants identified themselves as at least nominally Christian and five of the eight had been raised as Roman Catholics. Four rated their belief in a Higher Power as ‘extremely important’ to them. The other four rated their belief as ‘very important’ or ‘somewhat important' (mean rating for entire group was 3.8 out of 5). However, all but one participant noted that they had difficulty belonging to a church. Several were explicit that they felt traumatized by their childhood experiences of their mother's hyper-religiosity. Retrospectively, they viewed this as a symptom of their mother's schizophrenia, but in their childhood they had had difficulty distinguishing their mother's religious practices from her symptoms of mental illness.

Karen reported feeling "a form of post-traumatic stress" from praying in any group of people because of her experience of her mother's religious fanaticism. Her mother's fanaticism was reflected in the physical appearance of her parents' house as in addition to the many crucifixes on their walls (that she had a priest drip holy oil over that streaked down all the walls) her mother had also installed a holy water fountain at their front door just like in a church. When Karen was a teenager, her mother forced her, her brother and their father to pray the rosary with her nightly in her bedroom. Karen describes her mother's religious fervor as, "...an addiction almost, that was so dripping with Jesus. It was so uncomfortable, I felt like I wanted to take a shower afterwards, it felt gross (sighs with disgust)." Then one day her mother, who had never travelled outside the country, announced that she was going to a holy spring and shrine in Yugoslavia to seek God's blessings. Her father, who had once studied for the priesthood, did not want to dismiss her religious zeal as insanity and allowed her to go. Her mother brought with her a silver necklace of a butterfly that Karen had once given her. She submerged it in the spring and it allegedly turned gold in color. Her mother brought it home and showed Karen it was now gold to prove to her that God had blessed her. Even as a young teenager, Karen didn't know what to make of this. She thought, "Maybe it *was* a miracle, maybe God did change it to gold.” Then she wondered, “But, what does that prove, and why would God waste his time changing the color of someone’s jewelry? My mother doesn’t seem any better, so what good is changing her jewelry?”

Carol’s mother sometimes went out disguised as a nun due to her paranoia that people were spying on her. She also had a strong religious fervor and had torn down the wood paneling in their home and spray painted all the walls with Bible verses As an adult, Carol found that because she had been so worn down by her mother’s extremist behavior that she also could no longer attend religious services. Despite their aversion to attending church, both Karen and Carol described themselves as feeling a strong spiritual connection to God and both talked or prayed to God daily.

Donna, whose mother had religious statues and medals placed all over the house screamed her prayers at the top of her lungs in the middle of the night, every night, constantly waking everyone. Despite this traumatic experience, Donna has been able to maintain a tacit membership in the Catholic Church as an adult, but she rebels against her mother’s religious ostentation. She explained:

> …I feel like I have a spiritual connection with God and Jesus…but I don’t want to call it religion because my mother was such a fanatic. That word religion upsets me…But screaming prayers? [shakes her head no] …I think it should be quiet. You should go in a room and shut the door like it says so in the Bible. You shouldn’t scream your prayers, or if you’re going to fast you should do so with your hair combed and your face washed and a smile on your face. And don’t let people know that you’re fasting or that you’re whatever…It (one’s relationship with God) is not for show.

Only two participants had mothers who never displayed religious fanaticism. One of them, Holly, is the only participant who is fully active in a formal church today. She says that probably because her mother never coerced her toward religion, she enjoys belonging to her church and feels that the church members and her minister are vital sources of support to her. The other, Maya, reported that her mother had never been religious prior to illness, so her psychosis did not seem to involve religious themes.

Learning to live with unresolved feelings about the loss of mother to schizophrenia. Participants discussed continuing to feel unresolved as adults about the loss of their mothers to schizophrenia. Near the end of the interview participants were asked, "If you could tell your mother (in a way that she could understand) about your experience as a child trying to cope with her having a mental illness, what would you say to her (question 32)? " Carol spoke of the difficulty of feeling alone in the house as a child, with her voice sounding childlike as she spoke:

> It was really hard and there was just nowhere to go. There was no one to talk to. You were my mother and you were supposed to be there and you weren't there for me. Now I know why, but at that time, yeah, it was definitely… (trails off with sad affect). [Interviewer: That was the child speaking?]
> Yeah… yeah…yeah (voice grows quieter). [Interviewer: What would you want your mother to say to her?] That she's sorry (fights back tears)…

Steve spoke of wanting his mother to absolve him of his guilt for leaving her, and to understand that he needed to leave her to define himself in the world. He ended by stating wistfully that he would have loved it if his mother could have shared in his life and taken enjoyment from his success:

> I would say to her, I hope you understand why I did what I did…that I had to leave and I had to live my own life. I'd want her to understand that. I'd want her to enjoy what I've done, any one of my achievements in some way, that's what I'd like. Whether it's to see me perform (in dance) or to see something I've built or made (as a set designer). [Interviewer: What would you want her to say to you?] If she came to see something, I would love it if she enjoyed it and said how beautiful it was or how much she enjoyed herself…I would love it if she said that she did understand why I've lived the life I have… Well, there's two parts, there's longing for her understanding why I've been away, why I left her, but I also long for her enjoyment of my life, her sharing it.

Returning to the theme introduced in the section, mourning the loss of the pre-illness mother, offspring as adults continued to express their need to resolve the ambiguous loss of their mothers. As adults, they were still struggling to come to terms with their unmet longings to “be seen” by their mothers and to have an emotional connection with them. This theme will be elaborated further in the Discussion chapter.

Seeking therapy as adults. As adults, seven of the eight participants attended individual therapy. The average age at which they sought therapy was 26.6 years with a standard deviation of 6.7 years and a range of ages 20-39. The most frequent reason for seeking therapy was difficulty with a love relationship. In general, participants found their adult individual counseling ‘very helpful’ (mean rating 3.9 out of 5). Participants rated that their individual counseling addressed the issue of their mothers’ schizophrenia ‘some of the time’ but not ‘frequently’ (mean rating 2.3 out of 5). Steve who had eight years of individual therapy as an adult, illustrated the long term difficulty participants have had in making sense of their mother’s schizophrenia and their own emotional issues surrounding it. He said, “Just talking about my mother, I always seem to get nowhere. I seem to not even know what I want from talking about her. And getting in touch with what I’m feeling in the present is hard, and always has been hard.”

Lasting effects of parentification. For some participants the effects of being parentified created a pattern of defining themselves only in the caretaker role that lasted well into adulthood. In her adult life, Donna adhered to the role of caretaker both in her job as a nurse and in her family until her own children were raised. She then was the primary caretaker for her granddaughter for three years when her daughter-in-law could not care for her. However, when her granddaughter was given back to her mother, Donna was fifty-two at the time, became depressed as this was the first time in her life that she had existed outside of the role of caretaker. She described that her depression was exacerbated by her medical issues including severe arthritis. She has been unable to clean the house as she had been accustomed and could not partake in her usual hobby of sewing. Her physical limitations cause her to constantly berate herself for not being “the do-er” of the house as her mother had trained her to be. She felt it is like she has internalized her mother’s voice of criticism and she has trouble ignoring it:

> … (I constantly hear it) more like a question, like, why are you not sewing? Why haven’t you done this coat chest? You’re just sitting there, go do some laundry. Go do something! There’s all this to do, pick this up. Do something! Work on something. Keep going, keep doing. Do. Do. Do. I’m a human doing of a human being….I cannot just be.

In contrast to Donna’s experience, Laura who was also the oldest in the family, was not pushed into the parental duties by her mother. There was a time when she vaguely recalls things naturally heading that way as her mother did less and less, but she resisted the role and escaped into her peer group down the block. Having spent most of her time with peers, she feels she had a full childhood experience and did not miss out on anything. She later went away to college and soon after graduation got married. She and her husband then moved to another part of the country. However, she still did not get away scot-free from the pull of caretaking. After divorcing and living on her own for a number of years, she moved back into her parents’ home to help them manage the household, as it seemed they could not do it on their own. Being the oldest, she felt responsible to take the task upon herself and did not ask her siblings for any help. At the time of her interview, she had been living with them for three years. She was involved in a new relationship and planning to get re-married and move out on her own again. She said she planned to continue helping her parents after she moved, saying with a sigh, “You know, you’re never really done with them.”

After Robin graduated from community college when she was twenty-two, her mother, in addition to her active psychosis also became agoraphobic. First she stopped driving and then she refused to leave the house at all. Robin began to act in full as her caretaker. She said, “I now knew what my life would be. It was all planned: Supermarket, cigarettes, mom; supermarket, cigarettes, mom; me going to work; supermarket, cigarettes, mom.” Her mother not only kept her busy taking care of her, she also farmed Robin out to babysit her oldest sister’s children. Since her mother was unable to function as the babysitting grandmother, she sent Robin instead. Soon Robin was acting as a second mother to her nieces and nephews. For years she spent every weekend there as their primary caretaker while her sister went to work. Similar to Donna (described above), for Robin, the caretaking role soon became indistinguishable from who she was as a person. Even after her mother died of natural causes when Robin was twenty-eight, she moved back in with her father to care for him. When she turned thirty-seven, she finally realized that she needed to start her own life and decided to move from Florida to Pittsburgh to make a fresh start. Her father told her for the first time in her life that he was proud of her for finally putting herself first.

She made a good friend shortly after arriving in Pittsburgh three years prior to her interview. However, she attached herself to that friend and her husband in a caretaking role. She would constantly help them clean their house and do their yard work. Finally, through individual therapy she describes how she was finally able to withdraw from that role:

> It became, what do you guys need, not what do I need? I was like, oh you need to clean your house? I'll do it for you… You need your toilet scrubbed? I spent a whole therapy session on how I shouldn't feel the need to scrub their toilet (laughs).

She can now enjoy being with her friend without being her maid, although she still occasionally has to police her urges to over help her.

Advice for children currently living with mothers with schizophrenia. To close the interview, participants were asked, "What advice would you give to a child living today with a mother who has schizophrenia (question 33)?" Codes appear in Table 12 consisted of: *Believe in yourself / know your self worth, channel your anger into constructive things, express your feelings/ don't hold it in /talk with someone you trust, find another relative to live with/ don't stay with your ill mother, find other people who care about you (i.e. relatives, neighbors), get help /get counseling, have a sense of humor, keep a positive outlook, keep a positive self-image, keep positive relationships with your siblings /support each other, know that you have a right to be cared for, make friends /don't isolate yourself, rely on yourself /trust your instincts and your feelings, remember that your mother is not equal to her illness /she is a person, trust your 'healthy' parent /tell them how you feel*, and *use the arts (music, dance, drawing, etc.)to express your feelings.*

Participants' advice to current offspring children focused mainly on trusting themselves and their feelings, valuing themselves and knowing that they deserve to be cared for, not isolating themselves and finding someone to trust with whom they can share their feelings. They also recommended that they participate in the arts to learn to express their feelings through music, dance, and fine arts.

Participants advised offspring children to keep good relationships with their fathers and to work together with their siblings so they can support each other and make things more manageable in the home. Participants acknowledged that feeling angry is a normal part of the coping process. They advised channeling this anger into something constructive such as playing competitive sports, as a number of the participants did successfully. Participants' positive channeling of anger was likely also directed into their strong drive to succeed and in their focus on leaving the home as soon as they were ready to launch.

Interestingly, none of the participants advised the offspring children that their mothers are the victims of a devastating disease called schizophrenia and that the children are in no way responsible for causing this. As the feeling of being somehow responsible for their mother's illness appears to play a major role well into the adult lives of the participants, this would seem to be a crucial bit of advice that was overlooked. How the feeling of being responsible for their mothers' illness can remain a central conflict in the adult lives of offspring will be discussed further in the next section.

Continuing to feel responsible for mother's illness as an adult. At first, Holly did not think feeling responsible for her mother's illness continued to affect her as an adult, but as she discussed how she now does countless hours of volunteer work in addition to having a job, going to school and raising three young children alone, it occurred to her that her over-volunteering was probably a way she was continuing to prove she was "good enough." She also noted that if she buys something for herself, before she gets home she will often think of someone else to give it to who needs it more than she does. Her self-abnegation extends to her personal care as well as she typically will neglect her own make-up, hair and fashion to the point that some members of her church have offered to give her "a makeover." The extensive volunteer work she does is her way of "doing penance," she said, although she was unable to say why she felt a need to do penance.

Donna's comment at age fifty-six in discussing her religious beliefs reflects that she also continues to carry inner feelings of unworthiness:

> …I'm sort of afraid I'm going to hell because (my mother) said it so many times, that I have to be so perfectly good. I can't ever break any of the big rules. I have to be honest to a blemish.

Robin discussed that it was not until she was thirty-seven and contemplating suicide, that she was able to get herself into individual therapy. After some time in therapy, she could feel a major internal shift take place that allowed her to now say to herself, "My mother was mentally ill and it wasn't my fault." She reported that she no longer subscribes to her former belief that she is "a horrible person," for never being able to do enough for her mother.

Laura, at 37 years old and with a doctorate in Clinical Psychology, described how even though she knew as a child that her mother's illness was not her fault that she "still worr(ies) sometimes that it might be." When the interviewer told her "just for the record" it was not her fault, she broke down and sobbed for several minutes. She then recovered and said, "I guess I know it up here (in my head), but not down here (in my heart)."

Laura demonstrated that there is a great difference between knowing something intellectually versus emotionally processing the feelings associated with it. Her feelings of guilt and those of the other participants mentioned in this section, show us that offspring can be quite competent adults, yet under the surface still harbor misplaced feelings of responsibility for their mother’s mental illness and deep-seated feelings of unworthiness. Therefore i

In the Discussion section to follow, an argument will be made that better efforts must be made to help offspring obtain therapy as children that will help them to understand their mother’s mental illness and to teach them that they are not responsible for causing it. Hopefully, this will spare them from developing and carrying such toxic feelings of misplaced responsibility and unworthiness into adulthood.

CHAPTER V: DISCUSSION

Overview

The purpose of this study was to provide rich, biographical data on the lives of offspring of mothers with schizophrenia. The study was conceived as a qualitative, grounded theory study in order to build theory from the ground up from statements provided by the adult participants. Therefore, the study began with no pre-conceived hypothesis, but was simply open to whatever themes the adult offspring presented as they looked back on their life experiences. These themes were then analyzed to determine some of the common themes associated with growing up with a mother who has schizophrenia.

If one were to summarize in a single word the life experiences of these offspring, it would be ‘struggle.’ Offspring live their lives in a constant struggle to understand and deal with their mothers’ schizophrenia and the effects it has upon themselves and their families. Their struggle is both external and pragmatic (i.e. managing the problems of everyday life) as well as internal and psychological.

The life story presented by each offspring interviewed was greatly influenced by the central fact that he/she is the child of a mother with schizophrenia. Granted, there was a demand characteristic involved in this, as the main focus of the interview was on offspring’s lives in relation to their mother’s mental illness. However, interviews lasted three to four hours and broached a wide ranch of participants’ life experiences. Nevertheless, it became clear that offspring’s experience of their mother’s schizophrenia is the broadest thread woven through the tapestry of their lives. It affected every facet of their lives as children—family life, school life, and their social life with peers and others in the community. This fact defined their earliest relationship with their mother as primary caregiver and has influenced all of their subsequent attachment relationships well into adulthood. The results indicate that it may strongly influence their marital and childbearing choices, and in some cases possibly their choice of profession.

The pervasive intrusion of their mothers' schizophrenia into their daily lives necessitated that offspring live their childhoods under an enormous amount of stress. Not only did they struggle to get their developmental and emotional needs met but spent their lives at home "walking on eggshells," as several termed it, due to their mother's unpredictable mood fluctuations. Outside of the home they daily had to guard against their fears of stigma from peers and the community. However, the fact that only one of the eight participants was ever referred for counseling as a child suggests that the vast majority were resilient enough to manage this stress without displaying any notable negative behaviors (i.e. aggression, depression) in school or in the community that would have caused them to be referred for services. On the contrary, the majority of participants reported themselves to have been well-behaved and consistently in the average to honor student range in school.

In the Discussion we will first look at convergence points between the results of the present study and those of Susan Nathiel (2007) in her book, *Daughters of Madness: Growing Up and Older with a Mentally-Ill Mother.* Nathiel interviewed female offspring of mothers with various mental illnesses, a subset of whom had schizophrenia. As the similarities between offspring in the present study and Nathiel's offspring of mothers with schizophrenia will increase the validity of the present results, material from her book will also be cited wherever appropriate throughout this chapter. We will briefly touch on the effectiveness of the study design, review results that were noteworthy and link them to prior research. The major themes from the results of offspring's experience of their mother's schizophrenia will be elaborated, including their personal qualities and key strategies of resilience. We will look in more detail at the mourning process that offspring go through as a result of the ambiguous loss of their pre-illness mothers. We will discuss the lasting effects the experience of their mother's illness may have upon them as adults, and will compare issues faced by offspring of mothers with schizophrenia versus another stigmatized group, offspring of parents with alcoholism. We will then look at the clinical implications of viewing resilient processes in offspring as normative and make recommendations for improving the delivery of psychological services to offspring. Last, we will look at the limitations of the study and areas for future research.

Convergence Points with Nathiel's (2007) Study Increases Validity

The results of the present study have multiple convergence points with Nathiel's (2007) findings. Examples from three of Nathiel's participants, who were all daughters of mothers with schizophrenia, will be presented here.

The first participant, Eleanor recounted her experience of realizing that her mother was fundamentally different from the other mothers. This was similar to when participants in the present study spoke of learning that something was "not right" with their mother. She also alluded to her chronic feeling of "always being on the lookout for something bad to happen" around her mother, a feeling similar to what the participants in the present study called "walking on eggshells":

> Eleanor: Our next door neighbors had kids our age, and when we all started playing together, I really liked it at their house. It was lively, and the mother

> seemed to really like her kids—she smiled at them and at us. And the kids acted like they liked her back. They seemed relaxed and happy. There wasn't any of the tension of my house, the feeling of always being on the lookout for something bad to happen. Being at home felt even more depressive and heavy after I would hang out at the other houses and most other kids around seemed to have moms more like their mom, and I started to see how different my mother was. (p.67)

The second participant, June, spoke about feeling the need to keep her mother's illness a secret from everyone in the community. She was motivated to maintain this secret out of fear that revealing it would cause her to be separated from her sister:

> June: My mother was desperate to keep us with her. I always believed that if we were broken up, I couldn't be with my sister anymore. My mother would tell me not to say anything to anybody. I was very much into keeping the secret. (p.32)

The third participant, Tess, discussed how she employed the coping mechanism of adopting "an alternate family," similar to several participants in the present study:

> Tess: I worked with Portuguese people in the kitchen. I learned to be very responsible. I was always basically responsible, but I got rewarded. I developed a sense of identity. It was like my second family there. And it got me out of the craziness in my house. It was an escape, and I loved it. (p.137)

She also mentions another coping strategy—staying out of the house as much as possible—that was common among the participants of the present study. Interestingly, her comment that feeling part of this alternate family helped her to develop "a sense of identity," may indirectly suggest that her mother had been unable to provide adequate mirroring for her to develop her sense of identity. However, when placed in this more nurturing alternate family, her development seems to proceed. This theme will be discussed further in the later section on Reflective Functioning.

The present results and Nathiel's (2007) study have many more convergence points that are too numerous to list here. Additional excerpts from her study will be presented in later sections. The fact that these two studies were conducted independently and yielded data with multiple convergence points increases the likelihood that the present results are valid for female offspring of mothers with schizophrenia.

As Nathiel was writing for a women's series of books, she did not recruit any male subjects, so her study does not shed any light on the lack of males referring themselves for the present study.

Qualitative Design Allows Important Nuances to be Retained

The study followed a psycho-biographic approach and consisted of a 34-item, semi-structured, qualitative interview combined with a written questionnaire that provided demographic data and quantitative ratings on participants' sources of support. The qualitative design of the study allowed for important nuances in the data to be retained that likely would have been overlooked in a purely quantitative design. For example, in rating their sources of support, participants gave their mothers the lowest rating (mean = 1.1 of 5) out of the fifteen choices listed. However, when interviewed about their academic achievement, two of the participants reported that their main source of support for their academic success came from an unexpected source: their mothers. This indicated that a subset of the mothers were able to retain some splinter skills of parenting during their active illness phase despite their overall impairments. These data described in more detail below would have been lost in a purely quantitative design.

Both Maya's and Steve's mothers had been educators prior to illness. Maya's mother had been a substitute teacher and Steve's had been the director of a progressive pre-school. As children, their mothers helped to motivate and organize them, thus laying the foundation for their later academic success. For Maya's mother this was quite an achievement, as she had developed schizophrenia two years before Maya was born. She was still able to give Maya this support for her education even while her illness was active. She was also passionate about music and playing the flute and was able to teach Maya to play the flute as well. As described in the Results chapter, playing the flute became the cornerstone of Maya's identity in her social life as she joined the band clique at every level of school. Steve's mother post-illness, was not only able to continue guiding his and his sister's educations, but remained a resource to neighbors who wanted advice for their children's educational programs.

Another important area where the qualitative interview meshed well with and informed the written questionnaire data was in the area of participants' marital decisions and the child rearing choices of the offspring. These will be discussed in the next section.

Summary of Results

The study met its primary goal of describing the rich and varied life experiences of the offspring of mothers with schizophrenia. In the prior literature, offspring have been studied almost exclusively in "high risk" studies that assessed their assumed greater vulnerability to schizophrenia due to the genes they inherit from their mothers (Goldstein, 1987; Marcus et al., 1987; Tienari et al., 1987). In contrast, the focus of this study was upon offspring's resilient qualities and the strategies they utilized to achieve positive life outcomes despite the considerable challenges of overcoming maternal mental illness.

As the mean age of participants was 38.6 years (s.d. = 9.4, range= 24-56), most participants had enough life experience to look back with a good sense of perspective. One can get a better idea of their thoughtfulness and maturity by reading the three mini-biographies of representative offspring that appear in Appendix C. To my knowledge these are the first detailed accounts (with the exception of Tara Elgin Holley's autobiography) of the lives of offspring of mothers with schizophrenia to appear in the literature.

Results Obtained from the Written Questionnaire that were Noteworthy

1. Offspring had an earlier age of first marriage (mean = 22.2 yrs., s.d. =2.8, range = 19-25) compared to the general population of the U.S. (mean for females = 25 yrs.; mean for males= 26 yrs.)[4].
2. Offspring had a lower birth rate (mean = 0.9 children) than their mothers (mean=2.8 children).
3. Only one of eight participants received individual therapy or counseling as a child.
4. Six of eight participants received individual therapy as adults, first seeking therapy at a mean age of 26.0 years (s.d.= 6.8, range= 23-39)
5. The majority of participants (five of eight) were engaged in care giving professions as adults.

These results are discussed below.

Early First Marriage

Participants reported that when they first left home as young adults, they were seeking stability in their lives. Five of the eight participants sought this stability through early marriage (mean=22.2 years, s.d. =2.8, range 19-25). However, three of these five early marriages ended in divorce. The two marriages that remained intact had serious issues early on and the couples came close to divorce before resolving them. Participants felt that their marital troubles stemmed in part from their impulsive decisions to marry one of the first people they became involved with before they really knew what they

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[4] U.N. Economic Commission for Europe, Trends in Europe and North America (2001).

wanted in a partner. They also spoke of their own immaturity at that stage of life and felt that their early lives with their mothers had left them emotionally unprepared to fully commit to another person and to do the emotional work that marriage requires.

Several participants felt that as young adults they had contributed to continual upheaval in their love relationships. They saw this as a symptom of their habituation to the ‘crazy’ home life they had experienced with their mothers. In retrospect, they noted that they had felt bored when their love relationships felt too stable, and would unconsciously perform actions that caused conflicts to increase. They recognized that they had rejected potential stable relationships in favor of relationships that were more prone to ‘drama.’ However, this is not to say that offspring were unable to achieve a stable love relationship, because with time, and in some cases therapy, several ultimately did.

At the time of interview, four of the eight participants had a current spouse or partner. They noted, however, that they had to gradually learn to trust their partner and that this was sometimes a painstaking process. Offspring had to overcome their belief that they were fundamentally “unlovable” or somehow “not worthy” of having a trusting partner love them. Individual therapy helped several learn to manage these feelings of unworthiness so that they could improve their ability to trust their partners.

Reluctance to Have Children

For most offspring, their idea of finding ‘stability’ as adults and leading their own lives did not include having children. Only two of the eight participants had children of their own, and as noted above since the mean age of participants was 38.6 years, the majority had been through their child-bearing years. Compared to their mothers’ mean birth rate of 2.8 children per mother, participants' mean birth rate was significantly reduced to less than one child (0.9) per mother.

Six participants indicated that not having children was an active choice they had made due to their fears that their child or they themselves might later develop schizophrenia. As one participant put it, "I would never want to put a child through what I went through in dealing with my mother." The choice to not have children stemmed from their adherence to the view that the primary cause of schizophrenia is genetic, although several also believed environmental triggers such as moving away from familiar social networks to a new town and/or going through hormonal changes (i.e. due to giving birth or due to menopause) had also played a part in their mothers' development of schizophrenia.

Participants' fear of the genetic component of schizophrenia appears to be out of proportion with the reality of the genetic data that exists. Their bias may be a result of the emphasis in schizophrenia research over the past 30-40 years toward "high risk" studies that view the offspring of individuals with schizophrenia as being more strongly pre-disposed to develop schizophrenia than individuals in the general population (e.g. Marcus et al., 1987; Goldstein, 1987; Tienari et al., 1987).

The risk of schizophrenia for the offspring of a parent with schizophrenia (with no other family members affected) is approximately 9 out of 100 as compared to 1 out of 100 in the general population (Torrey, 2001; Andreasen, 2001). If the offspring has a child (i.e. whose grandmother has schizophrenia), that child's risk is approximately 5 out of 100 (Rozensweig, Leiman and Breedlove, 1996).

After all the years of “high risk” research, no model has yet been able to determine *which* offspring will be in the small minority who will go on to develop schizophrenia. As noted in the opening chapter, if we instead view the proverbial water glass as half full, children of mothers with schizophrenia have a 9 out of 10 chance of becoming healthy adults who will never develop schizophrenia. And grandchildren of those with schizophrenia have an even greater chance, 95 out of 100, of becoming healthy adults who will never develop schizophrenia. Should offspring starting their own families put aside their dream of having a child because of a 5% genetic risk factor? While a few might feel that’s too great a risk, it is conceivable that if offspring were educated that their risk of developing schizophrenia is 9 % and their child’s risk is only 5%, some would likely change their minds and have children of their own. In comparison, the prevalence rate for having a child with mental retardation is approximately 3 in 100 (Roeleveld, Zielhuis, and Gabriels, 1997),(although in their view the majority of these cases are not congenital and would have been preventable if the children had been raised in better environments). While the 3% risk for retardation is obviously lower than the 5% risk for schizophrenia in the child of an offspring, most women under the age of 35 barely consider the possibility that their child might be born with mental retardation, much less forego having a child for this reason. Offspring of mothers with schizophrenia need to be educated by their primary care physicians and obstetricians as to what their actual risk rates are in order to make better informed decisions on having children.

But participants’ choice to not have children is more complex than this. The qualitative interviews revealed an interesting other reason for several of the offspring’s stated choice to not want children. A subset of participants who were the oldest child in their families, in addition to their fear of the genetics of schizophrenia, also cited their having been parentified in their childhoods as another reason they did not want to have their own children. Having been forced as children to act as parents to their younger siblings caused them to feel that becoming a parent again would be too burdensome for them. Therefore, they chose to remain childless. This was not true of all participants who had been parentified, as two participants in this category did have three children each. The subset of parentified participants who wished to remain childless does not appear to be an aberration of the small sample size of the study. Some of Nathiel's (2007) participants also stated that their having been parentified was a major reason behind their choice to not have children.

The two participants that had been parentified who did have children of their own found that raising their own children was an extremely important source of support to them (5 out of 5 rating). They found that providing a stable home and being emotionally present with their children helped them to put their feeling of lacking these things in childhood in the past. The sad irony is that while all participants discussed their strong desire for a more 'stable' life as adults, the majority denied themselves the potential corrective emotional experience that having their own children might have afforded them.

Lack of Therapy as Children and Feeling Responsible for Mother's Schizophrenia

Only one participant, Maya, received therapy as a child. She rated her therapy as invaluable (5 of 5 rating) and emphasized the importance of her father being involved in some of her sessions. With the advice of her therapist, he gave her the message over and over that her mother had a mental disease and that Maya was in no way responsible for causing it. This allowed Maya, unlike the other participants, to be free of the feeling of responsibility for her mother's schizophrenia. The other seven participants never had therapy as children, although they felt it would have helped them understand their mother's illness and relieve them of their feelings of responsibility for causing it.

Recommendations for increasing access to therapy for children currently living with mothers with schizophrenia will be made in the Clinical Implications section below.

Seeking Therapy as Adults

Six of the eight offspring first received individual therapy as adults at a mean age of 26.0 years (s.d. = 6.8, range= 23-39), typically due to difficulty in a romantic relationship. They gave their adult therapy relatively high ratings (3.9 of 5) and rated the amount of time their therapy addressed the issue of their mother having schizophrenia as 'seldom' to 'some of the time.' Their introduction to therapy appears to come rather late considering the great emotional issues and conflicts raised by growing up with a mother with schizophrenia. It also appears that in about half the cases, issues surrounding their being the offspring of a mother with a severe mental illness were not sufficiently addressed. Again, recommendations for improving access and the focus of psychotherapy for offspring will be made in the Clinical Implications section.

Entering Care Giving Professions

Five of the eight participants were currently working in, training for or retired from care-giving professions. The effect size of this seeming trend may be exaggerated due to the recruitment method of this study. A survey with a larger sample recruited from the general public would be needed to evaluate its validity. It is possible that participants drive to "do things for others" which received the second highest rating on the supports questionnaire may, in part, be connected to their feeling of responsibility for their mother’s illness. Helping others may be their way of expiating their guilt. As Holly said in regard to her extensive volunteer service at a food bank, it was her way of “doing penance,” although she was unable to say what she was doing penance for.

Resilient Qualities of Offspring

Garmezy (1974, 1985, and 1987) first described ‘resilient’ children as having the ability to work and to play well and to hold high expectations for themselves. Benard (1991) added that they have a sense of personal agency, set goals for themselves, have good interpersonal problem solving skills and find meaning in life. While the present study did not employ any formal measures of personality or resilience, the life stories of the majority of participants showed that they generally demonstrated these attributes.

In the next section, we will discuss some of the personal qualities of resilience and the key resilient strategies that offspring successfully employed. Personal qualities included drive to succeed, good social skills, sense of humor and intelligence. Key resilient strategies were adaptive use of denial and avoidance, immersing oneself in the school environment and sports/activities, compartmentalizing home life from life with peers and school, making a conscious decision to leave home and break away from the family, and belief in a Higher Power.

Drive to Succeed

The highest rated source of support on the written questionnaire was ‘my own drive to succeed (mean= 4.6 of 5).’ Participants emphasized that they had of necessity become self-reliant at a young age. As a type of resilient event (for lack of a better term), they all made a *conscious decision* to do well in their studies and made a plan to get away from home. While ‘drive to succeed’ may seem like a simple attribute, it is clear whether one is talking about athletes, actors, businessmen or people in other endeavors, that a person can have intelligence, skills and personality but unless they have the extra quality of ‘drive to succeed,’ they will likely not achieve success at a high level.

Good Social Skills, Intelligence, Humor as Means of Bonding with Others

All of the participants presented as personable with good social skills. They were charming at many points in the interviews and displayed good intelligence and excellent senses of humor. These are all qualities that attract other people and assist in bonding with them. The interviewer was also impressed with their firm sense of loyalty to their mothers, families, and friends and even to their pets. These positive personality traits are likely to elicit positive responses from others. Most participants reported that they have historically attracted a lot of friends and bonded well with other people. Several participants as adults maintained a wide network of friends. Participants’ roles in these groups clustered around leader, comedian and counselor.

Key Strategies of Resilience

Adaptive use of Denial

The earliest key strategy in participants’ ability to overcome the effects of their mother’s schizophrenia was their adaptive use of denial. This denial allowed them to delay the reality of their loss of their pre-illness mother until they were old enough to begin dealing with this fact. This denial can be viewed as the child’s attempt to hold the ‘good mother’ in mind for their own developmental needs.

Avoidance and Compartmentalizing

Offspring employed the strategy of avoidance effectively to minimize their exposure to their dysfunctional homes. This meant joining activities after school and constructing social lives with peers in order to stay outside of the home and away from their mothers as much as possible. Sometimes offspring were able to bond with their friends' parents as surrogate parents of sorts, but more often they were reluctant to engage adults outside the family. Participants' descriptions of their strategy of avoidance meshed well with Nathiel's (2007) interviewees.

Participants in the present study compartmentalized their home lives from their lives in school or with peers in the community. They never invited friends home, but rather went to them, would not inform their mothers about events at school they were involved in, and they never talked about their mother or her illness to peers. For example, this was illustrated in Results by Steve's story of his friends discovering that his parents were divorced years after the fact, although they still had no clue about his mother being mentally ill.

These results were consistent with Nathiel's (2007) who also observed that children of mentally ill mothers frequently use the strategy of compartmentalization to keep their peer life separate from their home life. She writes:

> Resilient kids describe living in two worlds, taking pains that the two worlds don't collide. They learn to compartmentalize things so that their good experiences remain uncontaminated by their toxic home environment. It's a powerful coping ability, and part of what we see in the most resilient kids… (p. 78)

Immersing Self in School; Participating in Sports and the Arts

Participants' high levels of school achievement are in keeping with Garmezy, Masten and Tellegen's (1984) findings that above average intelligence and the ability to use the school environment as an area of competence and stability may serve as protective factors for children of mothers with severe mental illnesses. Offspring were also quite successful in their extracurricular activities such as playing sports, performing music and dance, babysitting, etc. The talents and resilience of these offspring was similar to that found in a subset of the children of schizophrenic mothers by Masten (1989) and Masten, Best & Garmezy (1990).

Making a Conscious Decision to Break Away from the Family

An extension of the avoidance strategy was that participants made a conscious decision to leave their mother's home as soon as it was possible to do so and then followed through. For Carol, this meant joining the British Army at age sixteen and being stationed in Northern Ireland. Her quip, "Dealing with terrorists was preferable to dealing with my mother," gives a good idea of how desperately she needed to get away. She felt that moving away enabled her to achieve a positive life outcome, noting that if she had stayed, she might have done violence to her mother because her anger toward her at that time was was so intense. Other participants more typically launched from the family by going away to college in their late teens, although several experienced a push/pull situation where they were continually returning home to try to resolve issues within the family such as their mother not maintaining a safe environment for their younger siblings (i.e. Donna's mother living with no heat in the home), or their mother appearing to be on the brink of a new breakdown (i.e. Steve's constantly being called home out of

University). Their need to keep returning to try to help their siblings and/or their mother may be viewed as them responding to survivor guilt that they carried into their young adulthoods.

Belief in a Higher Power

Most participants endorsed a belief in a Higher Power, although most avoided formal religion because of their exposure to their mother's hyper-religious, delusional behavior. [It should be noted, however, that the majority of the participants were raised as Roman Catholics, a church that has been losing general membership in the U.S. since the 1970's (Webb, Benay Joseph, Schimmel and Moberg, 1988)]. Karen, for example, recounted her mother forcing her and her brother as teenagers to pray the rosary nightly with her. This left Karen feeling like she had "a form of Post-Traumatic Stress toward praying in any group of people." Nevertheless, participants such as Karen still reported feeling sustained by their beliefs and their private spirituality. Several prayed almost daily.

Importance of Siblings and Peer Groups; Using Humor to Deflect Anxiety

The presence of siblings in the home appears to provide a prophylactic effect for children of mothers with schizophrenia. Their presence allowed offspring to feel that they were not alone in their struggle with their mother's illness. For example, Steve and his two younger sisters became "a team" that kept their household running. They used humor as a means of deflecting anxiety when dealing with their mother's angry verbal tirades by often laughing together at the absurdity of some of her statements. Robin's feelings of being abandoned by her mother as a young child were offset to some degree by her having two attentive older sisters who anticipated her needs so well that she felt it contributed to her language being delayed. Other participants such as Laura described how their group of friends was their most important source of support, becoming like an alternate family to them. Offspring who were oldest siblings were often parentified and although they often felt overwhelmed by the extra duties thrust upon them, also felt that they received emotional supplies from taking care of their younger siblings.

Offspring of Mothers with Schizophrenia Compared to Offspring of Parents with Alcoholism

The population that offspring of mothers with schizophrenia have the most in common with (outside of offspring of parents with other severe mental disorders) is the offspring of parents with alcoholism or substance abuse. For simplicity's sake, we will only focus on children of alcoholics here. A number of participants recounted that as children (and sometimes continuing into adulthood) they found it easiest to be friends with other children whose parent also had "a problem," such as alcoholism. Nathiel (2007) made a similar observation in presenting an anecdote describing the bond that one of her subjects, June, the child of a mother with schizophrenia, felt with a friend who had an alcoholic father and a drug abusing mother:

> June: I sometimes would tell friends she (my mother) was mentally ill, since it seemed in a way that everyone knew anyway. I did say that, but I still didn't let anyone come to my house, or whatever. When I look back at my friends then, they were all from alcoholic homes, so they all had secrets, too. We just gravitated together. We didn't really talk, but they got it. My friend whose mother was a pothead and whose father was an alcoholic, at two in the afternoon we'd move the bureau in front of her bedroom door, because pretty soon her father would be coming home and he would be drunk, and we didn't want him in there when he was drunk. We didn't talk about it; it was just, "Help me move the bureau."

Offspring of mothers with schizophrenia have a good deal in common with offspring of parents with alcoholism. Both groups have a parent with a disorder that causes them to not be fully present or functional; the parents' disorder causes stress and deleterious effects to the entire family system; there is stigma regarding both mental illness and alcoholism from the community; and offspring through their experience of stigma from the community develop a sense of shame regarding themselves and their families. Thus, offspring of both groups attempt to keep their parents' disorder a secret from peers and the community at large and both groups learn to suffer in silence.

Steinglass, Bennett, Wolin and Reiss (1987) in their book, *The Alcoholic Family*, describe how the day to day routines and social rituals of the family system of families with an alcoholic parent come to center around accommodating (or avoiding) the drinking behavior of the parent. Similarly, family life for families with a mother with schizophrenia must on a daily basis somehow accommodate (or avoid) the mother's schizophrenic symptoms including her flat affect, irrational thinking, poor communication, paranoia, avoidance of social situations (sometimes to the point of agoraphobia and never leaving the house), displays of odd or bizarre behavior, responding to visual and/or auditory hallucinations and attempts to convince the other family members that her delusions and paranoid ideations are true.

The results reflect that the daily routines and rituals of families of mothers with schizophrenia come to revolve around the ill mother in a similar way as in the families of parents with alcoholism. For example, Karen, who was engaged to be married at the time of her interview, discussed how she was missing the bride-to-be's typical happy ritual of planning her wedding with her mother because her mother's schizophrenia prevented her from being involved in this way. She also spoke wistfully of feeling unable to plan a dinner to celebrate the engagement in which her fiance's parents would first get to meet her parents. The uncertainty of her mother's social behavior made the idea of her mother attending the dinner party fraught with potential for shame and embarrassment. If no dinner was planned and the reason explained to her future in-laws, she was anxious about how they would respond when they learned that her mother had schizophrenia. Thus, to Karen the dinner seemed like impossibility in her mind. Karen's imaginings of how her wedding day would go were also tinged with fears of it becoming a shameful experience. She ruminated on variations of, "What if my mom suddenly yells out in the middle of the ceremony? What if people try to talk to her and she's unable to respond appropriately? What if she doesn't come and people say, 'It's her wedding day, shouldn't her mother be here?'" Even though she had dreamed about her wedding day since she was a young girl, she was considering abandoning the whole idea of a formal wedding. It just seemed impossible to accommodate her mother's presence (or absence for that matter) without risking great public shame to herself and to her family.

One can imagine the daughter of a mother or father with alcoholism similarly anticipating the possibility of a shameful experience at her wedding if her parent would become uncontrollably drunk. However, she might problem solve by having an alcohol-free wedding, or if serving alcohol, she might extract a promise from the parent to refrain from drinking at the reception. If the parent got drunk despite his/ her promise, their drunken behavior might in some cases be excused as anomalous over-drinking due to the happy event of the wedding. This type of excuse would not be available to Karen if her mother ranted incoherently at her wedding reception. So, from this comparison, the stigma of a mother with schizophrenia might be seen as greater than having a mother with alcoholism.

In terms of prognosis, there is also the possibility that the parent with alcoholism may one day get into treatment and become sober. While they may need to hit bottom before seeking help, and they might need to make great efforts to stay sober, the possibility exists that they could one day lead a normal life and be a normal parent free from alcohol. The prognosis for the mother with schizophrenia is poor in comparison. At present, there is no cure; there is only hope for a reduction in severity of symptoms if the mother can remain compliant with medication. Therapy may be of some supportive help and vocational assistance might help her keep a job that is not too demanding, but as things stand today, the offspring of the mother with schizophrenia must abandon hope that her parent will ever again be a fully functional adult or parent.

There is also a great disparity in the amount and availability of support services for children of alcoholics versus children of mothers with schizophrenia. Support groups for spouses and children of parents with alcoholism have now been widely known and available for decades (groups such as Al-Anon and Al-a-Teen). While some support groups exist for family members of the mentally-ill through organizations such as NAMI (formerly The National Alliance for the Mentally Ill), these programs are not nearly as widespread or well known. Only one participant in the present study, Carol, ever attended a support group for family members. She felt that getting exposed to stories about mothers with schizophrenia in other families helped her to distinguish what aspects of her mother’s behavior were symptoms of her illness versus what behaviors were intentional. She feels this perspective has helped her to approach her mother in a more dispassionate manner. A recommendation for possibly targeting mental health services to a combined group of offspring of mothers with schizophrenia and offspring of alcoholic parents will be made in Clinical Implications below.

Stages of Grief

Results indicated that offspring of mothers with schizophrenia may go though the five stages of grief: 1.Denial, 2.Anger, 3.Bargaining, 4.Depression and 5. Acceptance (Kubler-Ross , 1969) in regard to the loss of their pre-illness mother. Kubler-Ross says these stages may come in different orders for different individuals. Participants generally seemed to go through Bargaining as the second step (i.e. ideas like "maybe if I get good grades in school, my mother will be happy and get better"), with the Anger stage coming after as the third stage (i.e. ideas such as "I got good grades, but my mother is still not better. I'm so angry!"). For some participants, this anger manifested as anger against the self (the idea of "Why am I so bad, that my mother didn't get better?"), or anger at God for either giving their mother schizophrenia or for not curing her. The children felt discouraged and confused by the on-going nature of the loss of their mothers. Since there was no end point to the loss (as in physical death), offspring seem to have been unable to reach the stage of Acceptance during their childhoods. Some did appear to reach it as adults, but noted that Acceptance is an ongoing process that does not occur all at once. However, due to the ambiguous nature of their loss of their mothers, one would expect that offspring would be more prone to becoming frozen in one of these stages than are those processing the physical death of a loved one. We will discuss ambiguous loss further in relation to the work of Pauline Boss (2006) in the next section.

Ambiguous Loss of the Pre-Illness Mother

In her book, *Loss, Trauma and Resilience* (2006), Pauline Boss emphasizes that traumas within the family affect the whole family system, not just the affected individual. Participants recounted that their family systems had become paralyzed by their mothers' debilitation due to schizophrenia. Some of their mothers may have been able to retain some of the day to day functions of a typical mother (i.e. doing laundry, cooking meals), albeit with some difficulty. As one participant, Donna, succinctly described her mother's ability to cook, "She burnt dinner a lot." However, mothers with schizophrenia were unable to serve in what is typically the mother's most important function of being the emotional center of the family[5]

The family's experience of the loss of the mother was ambiguous—i.e. she was there in body, but she was not there as an emotionally present and fully functioning parent. Boss (2006) writes:

> Absence and presence are not absolutes. Even without death, the people we care about disappear physically or fade away psychologically. The Alzheimer's patient, the brain injured and the stroke victim, as well as the kidnapped or the imprisoned, are out of reach. The ambiguity between absence and presence creates a unique kind of loss that has both psychological and physical qualities. (p.1)

Boss (2006), whose early work on ambiguous loss was with families of soldiers missing in action, describes how the ambiguity of the mourning situation stops the social rituals that might have helped the family move beyond the loss. She writes:

> My basic theoretical premise is that ambiguous loss is the most stressful kind of loss. It defies resolution and creates long-term confusion about who is in or out of a particular couple or family. With death, there is an official certification of loss,

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[5] (N.B. A father could also serve in this capacity, but it is more often the mother).

> and mourning rituals allow one to say goodbye. With ambiguous loss, none of these markers exists. The persisting ambiguity blocks cognition, coping, and meaning making and freezes the grief process. (p. xvii)

When a family member has a physical illness or dies, friends and the community come together and support the family. They visit the ill person in the hospital or show support to the family at the funeral. They may send flowers or bring food to the house and these signs of support help the family to feel that they are not alone during their mourning process. However, when one's mother is hospitalized for being psychotic, friends and the community do not know how to react. They don't come to the hospital and sending flowers would be seen as inappropriate. When the loving, attentive mother is lost to mental illness, there is no ritual to help the family through the process. There is no socially appropriate way for friends and the community to show their support.

For the family operating under the stressful conditions of ongoing maternal mental illness, the words of the poet Yeats (1983) come to mind: "Things fall apart; the centre cannot hold." This applies to the family system as a whole, as well as the interior life of the child. Roles within the family shift—children are forced to act as parents to their younger siblings; bereft husbands may become emotionally absent from the family (through workaholism or emotional withdrawal) causing a second ambiguous loss for the children (i.e. feelings like '"Dad lives here, but he's never home," or "Dad's here but you can't talk to him about anything"). Conversely, fathers might also become too involved with their children. They might become enmeshed or overly controlling with them. In some cases, they might emotionally spousify their daughters. Siblings who might normally have positive bonds with each other instead tend to move into their own separate orbits. Children may become emotionally (and sometimes physically) neglected and left to fend for themselves. At the same time, their lack of experience in depending upon adults may stop them from reaching out to those adults who might serve in the role of surrogate parent or mentor. For the child's internal emotional life, things also tend to fall apart and the child has to constantly utilize his resilient qualities and strategies to hold himself together and to get his needs met.

Clinical Implications

To return to the opening theme of this paper, the field of resilience offers an alternative perspective to the "high risk" literature that has previously assessed offspring of mothers with schizophrenia. It is strength focused, rather than deficit based. In this paper, we saw the many substantial challenges that these eight offspring of mothers with schizophrenia faced and for the most part overcame. Being resilient does not mean you do not have any problems or flaws, it simply means that you use your resources, both inner and outer, to manage problems and reach positive outcomes.

Resilience May be Normative

As resilience research evolves, researchers are coming to the view that resilience is not a quality found in a select number of individuals who face adversity, but rather, a human capacity that we all share. Benard (2004) argues that resilience in children facing adversity is normative. After analyzing studies on resilience on children in a variety of contexts, she concludes:

> A consistent yet amazing finding over the last two decades of resilience research is that most children and youth, even those from highly stressed families or resource-deprived communities, do somehow manage to make decent lives for themselves. In fact, in just about any population of children that research has found to be at greater risk than normal for later problems…more of these children make it than do not. In most studies this figure seems to be 70 to 75 percent and includes children who were placed in foster care (Festinger, 1984), were members of gangs (Vigil, 1990), were born to teen mothers (Furstenberg 1998), were

> sexually abused (Higgins, 1994; Wilkes, 2002; Zigler and Hall, 1989), (or) had substance abusing or mentally ill families, (Beardslee, 1988; Chess, 1989; Watt, 1984; Werner, 1986; Werner and Smith, 2001)… In absolute worst case scenarios, when children experience multiple and persistent risks, still half of them overcome adversity and achieve good developmental outcomes (Rutter, 1987, 2000). (p.7)
>
> These findings confound a core belief of many risk-focused social scientists--that risk factors for the most part predict negative outcomes. Instead, resilience research suggests that risk factors are predictive for only about 20-49 percent of a given high-risk population (Rutter 1987, 2000); Werner 2001). In contrast, " protective factors," the supports and opportunities that buffer the effect of adversity and enable development to proceed, appear to predict positive outcomes in anywhere from 50-80 percent of a high-risk population. According to Werner and Smith, "Our finding and those by other American and European investigators with a life-span perspective suggest that those buffers [i.e. protective factors] make a profound impact on the life course of children who grow up under adverse conditions than do specific risk factors or stressful life events. They [also] appear to transcend ethnic, social, class, geographical, and historical boundaries. Most of all, they offer us a more optimistic outlook than the perspective that can be gleaned from the literature on the negative consequences of perinatal trauma, care giving deficits, and chronic poverty" (1992, p.202). (p. 8)

To take the view that resilience is normative, changes the way we would approach interventions for offspring of mothers with schizophrenia. If it is normative, then no individual offspring should be viewed as being pre-disposed to mental illness, and no offspring should forego having children out of the fear that their child will not possess the resilient capacities necessary to overcome a 5% genetic risk of developing schizophrenia.

Clinicians should view offspring as individuals whose progress is impeded by three factors: their membership in a dysfunctional family system; the impact of the traumatic effects of the ambiguous loss of their pre-illness mother; and survivor guilt (stemming from their belief as children that they somehow caused their mother's mental illness). If the offspring can work through these obstacles, than the offspring would naturally be able to make full use of those resilient capacities that we all possess.

Maternal Influence on Reflective Functioning of Offspring

It is generally accepted in psychology that the child's relationship with their primary caretaker, typically their mother, is the most critical relationship in their social and emotional development (e.g. Ainsworth, 1969; Mahler, 1975; Bowlby, 1977; Fonagy and Target, 1996). The quality of the child's attachment to their mother will set the pattern for the quality of the child's other significant relationships well into adulthood, if not for the entire lifespan.

Among the functions that the mother provides for the child is to serve a mirroring function for the development of the child's social self. As Bowlby (1988b) states, "…A child's self-model is profoundly influenced by how his mother sees and treats him, whatever she fails to recognize in him he is likely to fail to recognize in himself (p. 132)." Slade (2008) summarizes the concept of reflective functioning:

> The construct of reflective functioning (RF) was introduced over 10 years ago by a team of psychoanalytically oriented attachment researchers, Peter Fonagy, Miriam Steele, Howard Steele, and Mary Target (Fonagy & Target, 1996; Fonagy, Steele, Moran, Steele, & Higgit, 1991; Fonagy et al., 1995). Reflective functioning can be understood narrowly as the capacity to understand one's own and others' behavior in terms of underlying mental states and intentions, and more broadly as a crucial human capacity that is intrinsic to affect regulation and productive social relationships… The more that human beings are able to *mentalize*, or envision mental states in the self or other, the more likely they are to engage in productive, intimate, and sustaining relationships, to feel connected to others at a subjective level, but also to feel autonomous and of separate minds (Fonagy et al., 2002).
>
> While all human beings are born with the capacity to develop the reflective function, *early relationships* create the opportunity for the child to learn more about mental states, and determine the depth to which the social environment can ultimately be processed (Fonagy et al., 2002). A mother's capacity to hold in her own mind a *representation* of her child as having feelings, desires, and intentions *allows the child to discover his own internal experience via his mother's re-presentation of it.* A mother's capacity to make meaning of the child's experience will make him meaningful to himself, and allow him to go beyond what is apparent. (pp. 313-314)

The crucial concept here is that the child discovers himself and his internal experiences through the mother's "re-presentation" of them through the normal parental function of mirroring. Without sufficient parental mirroring, the child has difficulty seeing himself and defining himself. This causes the child to feel uncertain about his own boundaries. An example of a participant who had difficulty with self definition well into adulthood was Robin, who after moving out on her own for the first time at age 37, said she felt like the title character in the movie Runaway Bride, saying: "I didn't even know how I liked my eggs."

Maternal failure to provide adequate mirroring was also seen indirectly in one of Nathiel's (2007) participants, Tess. She describes how there was a mismatch between her internal image of herself and what she sees of herself outwardly. This was accompanied by her sense that her feelings felt "weird" or foreign to her:

> Tess: I was so sad growing up. You could see it in pictures. And I've even cut myself out of pictures because the picture that was there wasn't the image I hoped for. I was just devastated that I felt so awful and I knew that she (my mother) felt so awful. I was scared that what I felt was going to show and people were going to react to me that way. They'd react to me like I was weird-- and basically, I did feel weird. (p. 56)

One of Nathiel's (2007) other participants, Helen (whose mother's diagnosis is unclear, but who had several hospitalizations), shows how when the mother is impaired in her ability to serve as a mirror for her child's development, the child in fantasy may still be able to intra-psychically maintain an image of the "good mother" in order to get her developmental needs met:

> Helen: I remember having this sort of fantasy that I had two mothers. That I had one that was nice, and then an impersonator would come, the mean one. That's how I handled it in my mind, because my mother was a pretty warm, lovely woman, but when she wasn't feeling well, she was angry and distant. I really kind of thought of it that way. I can look back and understand that allowed me to keep

> my image of a “good” mother, because the mean mother wasn’t really the same person at all. (p.34)

It would be a mistake to interpret Helen’s fantasy of two mothers as a sign of maladaptive splitting, as her fantasy appears to have been an adaptive way for her to meet her developmental needs. It was a good solution for her to fend off anxiety that the world is a frightening place where a person we trust the most can suddenly and dramatically transform into someone we cannot even recognize.

A participant in the present study, Maya, who had never known her mother pre-illness, similarly kept an image of a mentally healthy version of her mother in her mind that she constructed based on things her father and other relatives had told her about her mother. She mourned that she would never get to share her life with this mentally healthy version of her mother.

Can Mothers with Schizophrenia be “Good Enough” Mothers?

A secondary focus of this study, in addition to the experience of offspring of mothers with schizophrenia, was whether mothers with schizophrenia can be “good enough” mothers (Winnicott, 1982). We saw earlier that two of the mothers in the active illness phase retained some splinter skills of parenting such as being able to push and focus their children’s educations. But, what of the mother’s overall ability to parent?

For the mother to provide “good enough” mothering, the mother must be attuned to the infant and his needs. Nathiel (2007) gives a good account of what attunement looks like when it goes well and when it does not:

> Research confirms what common sense already tells us: that all of those thousands of times that someone comforted us when we cried (or didn’t), all those times we were held (or not) and sung to (or not) and washed and changed and put down to sleep (or not), are all important. We do remember them, but we remember them more by the body/mind sense of what it was like to be there, not

> because we have memories of specific events. Did mother smile at us with her eyes, did she enjoy laughing with us, did we bring her pleasure? Or were we a burden, seeing ourselves reflected in her tired, distracted, depressed gaze? Even worse, did she see us as the cause of her unhappiness? Did she treat us as though we were the enemy, out to get her, out to cause her trouble? Did she glare at us, frighten us, hurt us, or just look through us as though we weren't there? (p.4)

Four of the eight participants had positive earliest memories of their mothers suggesting secure early attachments to them. They described their mothers prior to onset of schizophrenia as good, affectionate, functional mothers as far as they could discern as children. This early "good enough" mothering likely provided them with a buffering effect against later adversity. For example, recall Steve's earliest memory of his mother. It reflected what Winnicott (1982) would call an adequate holding environment:

> (I'm) playing with toys at their feet, like playing with Legos or something like that…She's there (with my father)…I'm aware of her presence…It's just a total family scene. They're reading and I'm playing. You know, it's quite peaceful. I'm engrossed in the toys, but I guess I'm feeling their protection over me.

Winnicott described that it is important for the mother to be there for the infant early on in a state of 'maternal preoccupation,' but then the mother needs to gradually move from this state to an environment where the infant is free to move and learn through experience. The infant then comes to learn that in addition to mother there is an "outside world (objective reality) which is not always there to fulfill his desires. When the mother is unable to allow the child to have time to explore on his own the child experiences 'impingement' upon his development.

Accounts of some of the other participants who had ambivalent earliest memories of their mothers suggest that their mothers likely were not able to consistently provide the attunement they needed, resulting in impingement on their children's development. For example, Maya, whose mother had schizophrenia prior to her birth, indicated that her mother was able to bond with her as an infant when Maya was fully dependent upon her, but when Maya was ready to move about and assert her own needs, her mother was unable to retreat and give her the space she needed to explore on her own and to learn to define herself. Her mother continued to make every decision for her: what she would wear, what she would eat, and what toys she would play with. This appears to have impaired, or at least delayed, Maya's ability as a child to come to a healthy sense of self as separate from her mother. When she first entered kindergarten, Maya could not separate from mother as shown by her vomiting in front of the school every morning for over a year when it was time to leave her mother.

Impinging upon her ability to engage with peers in her early schooling, was her difficulty observing the boundaries between herself and others, her trouble communicating her needs, and her feeling that joining with others was a form of abandoning her mother. This resulted in her teacher referring her for counseling. Eventually, her mother lost custody of her to her father. With the help of her therapist, her father began to train Maya to make her own decisions and to become more independent. However, an indication of the persistence of her early enmeshment with her mother is that even as an adult in her twenties, Maya reported she still often feels difficulty in making even simple choices, such as when presented with a menu at a restaurant.

A second participant, Donna felt she received good care from her mother as an infant. But, then her mother had a post-partum depression following the birth of her brother when Donna was four. When Donna was five, this moved into psychosis with her mother becoming hyper-religious, pinning religious medals all over the house and staying up all night screaming her prayers. Her mother began treating Donna as “a thing,” as “her do-er, not a person,” as Donna put it .Donna had to take care of the household and her younger siblings and her mother never allowed her to play with other children. This indicates that she did not view Donna as a person in her own right with needs and feelings. She saw her merely as an extension of herself, not as a child who needed time to play and to make friends in order to develop in a healthy way. While Donna still developed into quite a competent child, and adult --becoming a nurse, having a successful marriage, and being one of the few participants who raised children of her own-- her competence masked intense feelings of “not being seen” and feeling unworthy. During her interview (at age 56) her affect was still quite angry years later as she asserted tearfully but forcefully, “I am a *person*, not a thing!” She struggled with severe bouts of depression at important transitions in her life as when she first moved away from home to attend nursing school and when having her first child. She did somehow manage to be a caring and attentive mother to her three children despite her lack of a good maternal role model. We may view her ability to parent as an indication that her mother had provided her with “good enough” mothering from infancy to age four, when her brother was born and her mother became depressed. This likely gave Donna a strong foundation that could not be erased even by her mother’s subsequent mistreatment of her. (see Appendix C for her mini-biography)

Goodman (1987) studied the parenting ability of mothers with schizophrenia versus depressed mothers and controls. She described her results as follows:

> …Deficits were found in the child-rearing environment provided by the disturbed mothers. Both schizophrenic and depressed mothers were rated as less affectively

> involved and less responsive than well mothers. Schizophrenic mothers were rated as providing the poorest overall environment: less play stimulation, fewer learning experiences, and less emotional and verbal involvement. (p.419)

She also identified protective factors in the mothers that decrease their children's vulnerability: " lesser severity of illness, older age, higher education, higher IQ, work experience, and presence of a spouse, boyfriend, or other relative to help in child care (p. 420)." The protective factors that she mentions that apply to the mothers in the present study are work experience--all eight mothers had worked prior to marriage and illness, presence of a spouse--all eight mothers had a husband in the home to co-parent for at least the children's early childhood years (and four of these remained married and in the home throughout the participants' childhoods), and the higher education and high IQ in at least three cases where the mothers were college graduates with good to excellent grades. Older age of the mother did not apply to the participants. The last factor, level of severity of the mother's schizophrenia could not be gauged from participants' accounts and no medical records of the mothers were used in the study.

To answer the question as to whether mothers with schizophrenia can provide "good enough" mothering to their children, for about half of the mothers pre-illness, the answer would be yes. Half of the participants felt their mothers had done a "good" to "really good" job in raising them prior to illness. However, the answer would appear to be no for mothers in the active illness phase. As Goodman's (1987) study showed, children of mothers with schizophrenia fared less well on measures of neuro-cognitive development and social competence given yearly over three years, than did children of mentally healthy parents. Mothers with active schizophrenia controlled by medication may be able to maintain some of their parenting functions with the support of a spouse or another healthy adult in the home and other supports such as therapy for the mother. Therapy for the family as a whole would also be needed.

McFarlane, Link, Dushay, Marchal and Crilly (2004) advocate the use of Multiple Family Groups (MFGs) with a psycho-education component for all family members that contain an individual with schizophrenia. These groups combine several families that contain a member with schizophrenia and provide them with an expanded social network. Observing and interacting with other families in the group allow them to gain perspective on what behaviors of the schizophrenic members are strongly influenced by illness versus their distinct personalities. The groups are also helpful to the individuals with schizophrenia. Results of their study show "substantial reduction in relapse rates for patients with schizophrenia." Lowest rates of relapse were seen in those individuals who were on medication and who attended the MFG group with their family with an added psycho-education component for all family members.

Feeling Responsible for Mother's Illness

Participants who did not have the benefit of therapy as children seem to have had a life-long struggle with the feeling that they were somehow the cause of their mother's schizophrenia. For the most part, this feeling was unconscious. This was reflected in Carol's story (see mini-biography in Appendix C) about how her mother once beat a neighbor woman bloody with her high heel shoe. Even in telling the story during the interview, Carol said she still felt responsible for her mother beating the woman because the incident had started when Carol and the neighbor's children had been throwing rocks at each other. Another example is Robin's report that she always felt she was "a horrible person" because no matter what she did to try to please her mother, her mother never gave her any positive acknowledgement. A third example is Donna's constant fear that she was "going to hell." This feeling was still going strong in her fifties, reflecting the long-term effects that can occur when offspring children are left feeling responsible for either causing their mother's schizophrenia or failing to cure her through their own goodness.

The enduring power of the feeling of responsibility was demonstrated by Laura, a Ph.D. psychologist who was 37 at the time of her interview. As recounted at the end of the Results, she broke down crying when the interviewer told her that her mother's schizophrenia was not her fault and said she knew this in her head, but not in her heart. Her statement underlines the fact that knowing something intellectually is not the same as having processed it emotionally and thus becoming able to move on.

Survivor Guilt

The feeling of being responsible for their mother's illness also seems to dovetail into offspring appearing to carry a form of survivor guilt into adulthood. Several participants endorsed feelings of unworthiness. They felt that they were not entitled to good things of their own or to feel happy when their mothers were so miserable. For example, Holly reported that whenever she buys herself something, she will think of someone else to give it to who needs it more before she even gets home. She will then give away the item, denying herself. One of Susan Nathiel's (2007) participants, Pat, also reflected offspring's difficulty in allowing themselves to feel happy without experiencing guilt at the same time:

> Pat: The biggest negative impact overall (of my mother's mental illness)? I think I've had to generate my own fuel. I never thought of it that way before, but I've never felt that I've had anybody behind me. I feel like I started with an empty tank. I never felt entitled to my own happiness. I think being happy is scary for

> me. It’s like, if she’s in so much pain, literally and figuratively, how can I be disloyal and be happy? That lack of entitlement is part of the rhythm of everyday life... (p.173).

Offspring’s feelings of guilt and unworthiness may have been inadvertently reinforced by fathers who tended to focus on protecting the mother from the emotional vicissitudes of life. Their more pragmatic motivation for taking this focus might have been to prevent disruptive, angry tirades from the mother.

The feeling of survivor guilt was particularly hard for the offspring who were parentified children at the point when they leaving home for the first time. Not only were they leaving their mothers, but they were also leaving behind their younger siblings whom they had cared for. This was illustrated in Donna’s story (see appendix C) of competently pushing herself forward into nursing school, only to become severely depressed shortly after leaving home. This was triggered by her learning that her mother and younger siblings had no heat in their apartment. Similarly, Carol couldn’t leave her brother behind when she joined the army, so she arranged for him to go live with an aunt before she left. Steve was constantly called back from college by his younger siblings who told him his mother was on the brink of another breakdown. Karen went away to college, but dropped out mid-semester because she worried about leaving her father behind to care for her mother alone.

Pragmatically speaking, given the great limitations on mothers with schizophrenia for organizing their households and caring for their children, it was necessary that these older siblings to fulfill some of the parental functions so that the household could run at all. However, for parentified offspring to be in this position without support or recognition from adults appears to put them at great risk for anxiety and depression, hidden beneath their outward demeanor of competence. This is where therapy as children would have been helpful to them.

Improving Access to Psychological Services for Offspring

The lives of offspring would likely have been greatly improved by having therapy as children or adolescents. This could have helped them to understand that their mothers had a mental illness and that the offspring did not cause it. This would help relieve their feelings of responsibility for their mother's schizophrenia and may have prevented, or at least diminished the sense of survivor guilt that many of offspring continued to carry through adult life.

The result that participants first sought individual therapy as adults at a mean age of 26.0 (typically to deal with difficulty in a love relationship) indicates that opportunities to participate in therapy were missed not just at the elementary, middle and high school levels, but were often missed at the college level as well. Given the amount of shame and guilt that offspring of mothers with schizophrenia typically carry until they become involved with therapy, it would be extremely helpful if psychological services were made expressly available to them at every level of school, especially the high school level, a time period where a number of participants first became willing to disclose their mother's schizophrenia to a selected peer or adult. Because offspring appear to have a built in distrust of confiding in others due to their ingrained experiences of stigma surrounding mental illness, interventions should be expressly targeted to them. For example, high school or college psychological services could post flyers inviting students to come to psycho-educational lectures/discussions on parental mental illness and/or alcohol/substance abuse. At these events they might invite students to confidentially sign up for brief individual or group counseling sessions, and longer term therapy may become an extension of that if needed. If psychological services are not targeted in this manner but just made generally available, it is unlikely that offspring of mothers with schizophrenia will refer themselves for services.

Improving Access to Treatment for Mothers with Schizophrenia

The subset of mothers who had a mean delay of 12.7 years before receiving any form of psychological treatment reveals a gaping hole in the mental health delivery system. With the advent of the latest generation of anti-psychotic medications such as Risperdal that no longer cause as many side effects as previous generations of medications, it is unconscionable that individuals with one of the most severe forms of mental illness should be left untreated for 12 and a half years. For the offspring of these mothers, the delay in treatment meant they spent their entire childhoods with mothers who displayed unrelenting, full-blown symptoms of schizophrenia. They and their families had to cope as best they could for that time period with no guidance from anyone representing the mental health system.

A major problem offspring had in getting help for their mothers was described by several participants. This was their mother’s ability “to fool” mental health professionals by “acting normal” for the limited amount of time of a psychiatric interview, typically no more than half an hour. Several of the mothers would have been diagnosed and treated years earlier if professionals had done longer and more thorough assessments.

Primary care physicians are the gatekeepers to medical services for the majority of Americans and could play a crucial role in expediting psychiatric services for mothers with schizophrenia and individuals with other mental health disorders. They could do this by screening their patients for psychiatric issues once per year at their annual check-up. This would mean they would need training in being alert to psychiatric issues and in administering a brief screening instrument to assess them. Two participants discussed incidents where their mothers were ranting in an illogical and paranoid fashion in front of their medical doctor, and the doctor addressed the presenting medical issue that brought them to the appointment, but completely ignored the clear psychiatric issues. Primary care physicians can and should be involved in improving psychiatric services for all patients with mental health disorders.

Limitations of the Study

The limitations of this study are its small sample size of eight and that the sample consisted of seven females and only one male. The original project design called for interviewing 12 participants, six female and six male, but even after substantial recruiting efforts only eight qualified individuals referred themselves for the study. While we can assume that there are an almost equal number of male and female offspring of mothers with schizophrenia, for whatever reasons males were reluctant to refer themselves for this type of interview study.[6] (The one male who did participate was not self-referred, but was recruited by direct request, word of mouth).

Nathiel (2007) wrote her study for a woman’s series publication and thus did not attempt to recruit any men. She did, however, mention two brothers of her female subjects who developed emotional and drug problems in adolescence. She said, “This isn’t surprising as boys tend to act out and abuse substances to help them manage emotional pain,” whereas girls are more likely to become depressed, develop eating

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[6] Although it is well established that women volunteer for psychological studies at higher rates than men do as shown, for example, in the work of Martin and Marcuse (cited in Rosenthal, 1965).

disorders, or self-mutilate (p.75).” Similarly, two participants in the present study indicated that they each had a brother who had gotten into alcohol or drug use. While these numbers are too small to identify a valid trend, it is possible that male offspring of schizophrenic mothers are more prone when under stress than females to resort to externalizing behaviors, and alcohol/substance use. This response strategy is the antithesis of discussing one’s experiences and feelings in an interview such as the present study. As there was only one male participant in the study, these results cannot be readily generalized to male offspring of mothers with schizophrenia. They are, however, representative of female offspring.

Areas for Future Research

Further research is needed to assess the life experiences of both fathers and sons in families with schizophrenia. If these perspectives could be obtained and combined with the present study, we would have a comprehensive view of life for all family members of mothers with schizophrenia.

Nathiel (2007) study shows that the experiences of offspring of mothers with schizophrenia overlap to some degree with those of offspring of mothers with other psychiatric disorders such as depression, bipolar disorder and borderline personality disorder. Further research is needed to distinguish the extent of the overlaps in experiences for offspring of mothers in each of these categories.

Appendix A

Interview Questionnaire

1. Tell me about yourself in terms of your education, current employment and career path? What led you to choose the career path that you did?

2. Tell me about your current marital and living situation. With whom do you live and what are your current family circumstances?

3. Tell me a little about yourself apart from your job and your family role? What activities do you really like to do and what would you really like to do in the future?

4. What is your earliest memory of your mother? Please describe this in detail, i.e. how old are you, where are you, how do you feel about what is happening in the memory?

5. Tell me about your mother prior to her illness, if you can. What was she like as a person? Did you know her before? (If you did not know her then or were too young to remember, what have you heard about her from other people regarding what she was like prior to her illness)?

6. Tell me about your mother's talents and achievements prior to her illness. For example, what level of education had she achieved, what kind of work did she do (if any), how did she like to spend her time and what were her plans for the future?

7. What was family life like for you before your mother became ill and in particular what was your relationship like with your mother before she became ill?

8. About how old was your mother when she first displayed noticeable symptoms of mental illness and how old were you at this time? How much did you understand at the time about what was happening and what were your feelings about it?

9. In what ways did your mother change as a result of her illness in terms of her personality? In terms of how she interacted with you and the rest of your family? Were these changes sudden and dramatic or did they occur slowly over a long period of time?

10. Please describe how your relationship with your mother changed as a result of her illness?

11. How did your father and /or other relatives respond to your mother's illness? Did he or they try to discuss her illness with you and if so how did he or they explain things to you?

12. As a child how aware were you that your mother had a mental illness and how did your ideas about this change over time? Looking back retrospectively as an adult, in what ways do you think your mother’s illness affected you as a child.

13. Looking back retrospectively as an adult, in what ways do you think your mother’s illness affected you as a child?

14. What kinds of changes took place in your childhood household as a result of your mother’s illness? In what ways did family responsibilities and roles change?

15. In what ways if at all was your mother able to continue functioning as a parent to you after the onset of her illness? Who, if anyone, took up the functions of parenting which she was no longer able to fulfill? How well met were your emotional needs? Please describe

16. Was your mother ever hospitalized in your childhood and if so what were those separations like for you?

17. How, if at all, did having a mother with a mental illness affect your childhood relationships with friends and adults in the community?

18. As a child how did you feel about sharing information about your mother with others? Did you ever feel that you had to keep your mother’s illness a secret and what did you imagine would happen if this secret was revealed to others? As an adult have you told others about your mother’s illness and if so with whom and how did you feel about sharing this with them?

19. In what way(s), if any, does the experience of growing up with a mother with schizophrenia continue to affect you know as an adult in general? As a parent?

20. Who and/or what were your sources of support during your childhood in the time period(s) when your mother was ill? Who and or what kept you going?

21. Tell me about your relationships with your siblings. Did your mother’s illness affect you all the same way or differently? In what ways did having siblings help you or not help you in dealing with your mother’s illness?

22. What was it like when you first moved away from home, i.e. to attend college or to live in your own place? Was separating from your mother and family easy or difficult or a combination of both and why?

23. What have romantic relationships been like for you? What aspects of relationships are easy or hard? What effect if any has your mother’s illness had on your ability to enter into and sustain love relationships?

24. How did you meet your spouse or partner and what about him convinced you that he was the right person to be with?

25. What personal qualities do you most admire in your spouse or partner and why? What qualities do you dislike? How do you and your spouse resolve disagreements and what issues, if any, seem to be chronic sources of disagreement?

26. Tell me a little about your children (if applicable) and your relationship with them? What aspects of parenting are particularly hard or easy for you?
[If not applicable]: What are your feelings about becoming a parent in the future? What aspects of parenting do you imagine would be easy or hard for you?
[If interviewee expresses no interest or desire to become a parent, probe further]: How did you come to the decision to not have children? How, if at all, is this decision connected to your experience of having a mother with schizophrenia?

27. At times when life feels difficult, describe what sustains you, i.e. a relationship(s), religious beliefs, a philosophy, an attitude, etc. or what combination of things?

28. Describe the personal qualities in you that have allowed you to overcome the difficult circumstances of having a mother with schizophrenia? What are the sources of your resilience?

29. How, if at all, have your feelings about your mother changed over time? Did a particular event(s) in your life cause your feelings to change (i.e. getting married, having a child)? Describe your internal odyssey in coming to an understanding of her illness.

30. Have you ever been afraid that you yourself might become mentally ill and if so how have you overcome this fear?

31. Did you ever attend any form of counseling as a child? As an adult? If so, was the issue of having a mother with schizophrenia a prominent one in the discussions or not? In what ways was counseling useful to you or not?

32. If you could now tell your mother (in a way that she could understand) about your experience as a child trying to cope with her having a mental illness, what would you say to her?

33. If you met a child today who was living with his/her mother who had schizophrenia, what advice would you give to him or to her?

34. Is there any aspect of your experience growing up with your mother that was not covered in this interview, but which seems important to you? Please discuss that now.

Demographic Questionnaire

Please answer the following questions completely. Your confidentiality is assured. You may skip any question that you do not feel comfortable answering.
DO <u>NOT</u> WRITE YOUR NAME ON THIS FORM.

1. Participant's Code Number (entered by interviewer): ________

2. Your current age: ______

3. Your gender (circle): male female

4. Your highest level of education completed (circle one):

grade school high school some college college(B.A.) grad school

5. Please fill-in your current occupation: ____

6. Your current marital status (circle one):

single/ never married	living with partner	married	separated	divorced

7. How many years have you been with your current spouse or partner (include years dating): ________

8. Your age when you first married (if not married, age when you moved in with your partner): ________

9. If you have been married more than once, please give a brief thumbnail of your marital status changes including your age at each major event:

____

____

____

____

10. How many children do you have? _______

11. How old were you when your first child was born? _______

12. Please list the gender for each of your children and each one's current age:
(For example: "boy-17, girl-15" etc.)

____

____

13. How many of your children currently live with you full-time? ____ part-time_____?

14. How many brothers and sisters do you have? _____ brothers ______sisters

15. How old was your mother when she gave birth to her first child? ______

16. How old was your mother when she gave birth to you? ________

17. Please fill in your birth order rank among your siblings (for example "3rd of 5 children")?

____

18. Is your mother currently living (circle)? Yes No

19. What is your mother's current marital status? (circle):

married divorced separated widowed single/never married

20. If your mother is living, where does she reside (circle one)?

With spouse/partner	Lives alone	In home of one of her children
Supported Residence	Hospital	Nursing Care Facility

Other:____________

21. How old was your mother and how old were you when she FIRST displayed clear symptoms of schizophrenia (i.e. delusions, hallucinations, confused thought and speech, etc). (If this was before you were born, please try to estimate how many years before you were born)?

Mother's age: ________ Your age: ________
(Or ______ years before I was born)

22. How old was your mother and how old were you when a medical doctor first diagnosed her with schizophrenia (or any schizophrenia spectrum disorder)?

Mother's age: ________ Your age: ________
(OR ______ years before I was born)

23. How many times, if at all, has your mother been hospitalized for mental illness during YOUR lifetime (circle):

0 1 2 3 4 5 more than 5

24. For EACH of your mother's hospital stays for mental illness please ESTIMATE the duration of her stay in days, weeks OR months. Please list her approximate age AND your age at the time of EACH hospital stay*:

						Mother's age	Your age
Stay 1	_____	days	_______	weeks	______	months ___________	_______
Stay 2	_____	days	_______	weeks	______	months ___________	_______
Stay 3	_____	days	_______	weeks	______	months ___________	_______
Stay 4	_____	days	_______	weeks	______	months ___________	_______
Stay 5	_____	days	_______	weeks	______	months ___________	_______

*(if more than 5 hospital stays, list the 5 longest stays above).

25. Who was your primary caretaker during the time(s) when you were a minor and your mother was hospitalized (or not living with you for reasons of mental illness)?

____

____

____

____

26. If your mother was EVER prescribed medication for schizophrenia, please rate her general compliance with taking her medication (circle one)?

Not Applicable Poor Fair Good Excellent

27. What types of counseling have you ever attended (circle all that apply) and fill in your approximate age (or range of ages) that you attended these?

None	Individual	Group	Family	Marital	12-Step Program
Your age(s) of attendance:	________	_______	_______	________	________

28. How helpful to you was the counseling you attended (circle one)?

0	1	2	3	4	5
not helpful at all	not very helpful	a little bit helpful	fairly helpful	very helpful	indispensable, it changed my life

29. How often did the counseling you attended directly address the issue of your mother's mental illness (circle one)?

0	1	2	3	4	5
never	seldom	sometimes, but less than other issues	as often as other issues	more often than other issues	all the time, it was the main focus

30. As this study is concerned with emotional and psychological resilience, please RATE HOW IMPORTANT each of the following has been to you in your life as a support for you and your resilience. CIRCLE ONE NUMBER FOR EACH ITEM (0=not important, 5=extremely important):

My father	0	1	2	3	4	5
My mother	0	1	2	3	4	5
My siblings	0	1	2	3	4	5
My grandparent(s)	0	1	2	3	4	5
My partner/spouse	0	1	2	3	4	5
My children	0	1	2	3	4	5
Other relative(s)_________	0	1	2	3	4	5
A friend(s)	0	1	2	3	4	

My belief in God or a higher power	0	1	2	3	4	5
My own drive to succeed	0	1	2	3	4	5
A teacher	0	1	2	3	4	5
A counselor	0	1	2	3	4	5
A coach or activity moderator	0	1	2	3	4	5
A pet(s)	0	1	2	3	4	5
Doing things for others	0	1	2	3	4	5

THANK YOU FOR TAKING THE TIME TO FILL THIS OUT. PLEASE RETURN YOUR COMPLETED FORM TO THE INTERVIEWER.

Appendix B

Table 1. Sources of support questionnaire. Participant ratings for "How important has each been to you in your life as a support for your resilience?" (0= not important, 5= extremely important)

	Mean	[N]	Range
Children (my own)	5.0	2	5- 5
My own drive to succeed	4.6	8	3- 5
Doing things for others	4.4	8	2- 5
Friend(s)	4.4	8	2- 5
Spouse/Partner	4.3	6	3- 5
Belief in God/Higher Power	3.8	8	2- 5
Father	3.6	8	1- 5
Siblings	3.6	7	2- 5
Other Relative(s)	2.3	8	0- 5
Teacher(s)	2.3	8	0- 5
Grandparent(s)	2.1	8	0- 5
Pets	1.9	8	0- 5
Counselor(s) (child)	1.7	8	1- 5
Coach or Activity Advisor	1.7	8	0- 5
Mother	1.1	8	0- 3
Playing Music [write-in]	5.0	2	5- 5

Table 2. Codes for earliest memory of mother: positive attachment (q. 4)

Able to explore/ pursue goals
Can rely on mother /trusts mother
Comfortable being alone
Early mother enjoys being a parent
Early mother is loving /caring/expresses affection
Feeling mother's protection/ feeling safe with mom
Feeling positive bond with early mother
Makes friends easily
Pre-illness mother is functional as adult and parent

Table 3. Codes for earliest memory of mother: ambivalent attachment (q. 4)

Ambivalent early memory of mother
Feeling alone
Feeling anxious re: separating from mother
Feeling mother wasn't there for me / can't trust mother
Feeling pushed away by mother
Feeling need to be around people (as adult)/ uncomfortable being alone
Feeling shy and insecure as child
Mother treats child as an extension of herself/ "a thing" (not a person)
Not feeling a bond with mother.

Table 4. Codes for first learning that "something is wrong" with mother (q. 8)
Anxiety/worry
Anger at God (for making mother ill/for not curing mother)
Anger at mother (for not being emotionally available)
Becoming hyper-vigilant to mother's moods
Blaming father (for not getting mother help)
Feeling confused by changes in mother
Feeling depressed /withdrawn
Feeling lack of information (re: what's wrong with mother)
Feeling powerless (to help mother)
Feeling responsible for causing mother's illness /doing penance
Feeling that something is "not right" with mother
Nightmares/ changes in sleep
Walking on eggshells (around mother)

Table 5. Codes for mourning the pre-illness mother (q. 8)
Bargaining with God
Feeling constrained in expressing feelings of loss (due to ambiguity of situation)
Feeling lack of mother's attention
Feeling that early mom died
Feeling that early mother "died"
Losing contact with extended family
Mother is a different person (than pre-illness)
Trying to be extra good (so mother will be happy again)
Unable to express feelings of loss (due to social stigma)
Using food as solace (for losing mother)

Table 6. Adapting and coping with mother's active illness (q. 20)
Adopting a loose alternate family (friend's family; school)
Avoiding negative feelings /suppressing feelings
Bonding with peers (whose parents also have MH or alcohol issues)
Compartmentalizes family life from school/peers
Denial /positive use of denial
Enjoys helping others /enters helping profession
Focuses on escaping family (to college, army)
Focuses on personal goals
Immerses self in peer group
Immerses self in school
Immerses self in sports/activities
Leader of peer group /likes being in control
Making a conscious decision to break away (from mother/ family)
Personality shifts from shy to gregarious
Playing outdoors/ away from home
Prefers male friends (as means of limiting social conversation re: mother)
Reading books (as outlet/escape)
Staying out of house as much as possible

Teaming up with siblings (to run household)
Tells self situation is temporary /stays future-focused
Uses humor as means of bonding with others
Uses humor to keep others at comfortable emotional distance

Table 7. Codes for sources of support (q. 20)
Caretaking /doing things for others (heals self)
Father/ relying on "healthy" father
Friends (early/ middle childhood)
Friends (adolescence)
Friends (adulthood)
Pets (giving/receiving unconditional love /affection)
Playing music (i.e. piano, flute) /bonding with mother through music
Pursuing a dream /goal
Siblings (feeling support from their shared experience)

Table 8. Codes for keeping mother's schizophrenia a secret (q. 18)
Always played at friends' houses (not my own)
Compartmentalizes home life /never invites friends home
Does not invite mother to school events
Experiences stigma from community (re: mother's appearance /behavior)
Fear of being found out /being teased, shamed by peers
Feeling shame re: mother's mental illness
Family does not discuss mother's mental illness
Family members use only euphemisms to refer to mother's schizophrenia
Fears father's anger (if offspring speaks of /discloses mother's illness)
Fears mother will be locked up if illness is disclosed
Fears siblings and self will be placed in foster care
Has never discussed mother's illness with anyone (until interview)
Keeps mother's illness secret from peers
Keeps mother's illness secret from teachers/adults

Table 9. Codes for disclosing mother's schizophrenia to others. (q. 18)
Bonds with friends whose parents also had issues (MH/ alcohol)
Discloses mother's schizophrenia to best friend
Discloses mother's schizophrenia to coach/ activity advisor
Discloses mother's schizophrenia to partner/spouse
Discloses mother's schizophrenia to teacher/
Discusses mother's schizophrenia with therapist (as adult)
Mother inadvertently discloses illness to community through erratic behavior
Talks about mother's schizophrenia freely (as adult)

Table 10. Codes for moving away from home for the first time (q. 22)
Becoming anxious/depressed after leaving home
Escaping into college social life /avoiding contact with mother/family
Feeling confident/ maintaining a "can do" attitude

Feeling manipulated by mother (to return home)
Feeling survivor guilt (re: leaving siblings, mother behind).
Feeling separation anxiety/ homesickness
Feeling obligated to return home to help mother/siblings
Making a conscious decision to leave
Making a conscious decision to leave
Returning home/ responding to pull to “save” mother
Taking advantage of opportunities
Worrying about mother
Worrying about siblings

Table 11. Codes for functioning in romantic relationships (q. 23)
Attractive to others / no trouble getting dates
Avoids expressing anger/discontent to partner (fears being seen as “crazy”)
Casual dating is easy
Dating is a “fun” escape
Difficulty expressing feelings to partner / feels like “learning a new language.”
Does not bring dates home /arranges to meet dates away from the home
Dumped after boyfriend hears story of mother’s illness
Expects partner to “magically know” what he/she wants (without being told)
Feeling controlled in marriage/relationship
Held anger causes loss of libido (in marriage)
Keeps mother’s illness secret from date/ partner
Lack of emotional intimacy leads to divorce
Lack of healthy parental role models for intimacy
Marries quickly after dating for only brief period
Mother makes delusional accusations re: dating to offspring (i.e. “You’re a prostitute.”)
Not interested in dating / i.e.”It’s too much trouble” (due to issues with autonomy)
Passive in relationships /does everything partner’s way
Serious dating feels more difficult
Troubles with intimacy
Trusting partner is initially difficult /learns to trust but is a long process

Table 12. Codes for what sustains you internally (an attitude, philosophy, belief, relationship?) (q. 27)
Acceptance of life’s highs and lows
Being with friends
Belief in God /Higher Power
Breaking cycle of self-blame /controlling negative thoughts
Giving support to others (friends /those in need)
Keeping a positive attitude
Keeping a sense of humor
Logical thinking /reasoning with self
Participation in formal religion
Philosophy that life is just
Spiritual relationship with God (apart from formal religion)

Striving for balance (in life)
Taking care of (own) children/ grandchildren

Table 13. Codes for sources of resilience/ personal qualities that have allowed you to overcome your experience of your mother's schizophrenia (q. 28)

Ability to identify with and emulate role models
Ability to be emotionally present with others
Ability to make and keep friends/ good social ability
Ability to seek help /therapy
Ability to separate /individuate from family
Ability to trust others (despite early loss of relationship with mother)
Capitalizing on opportunities
Desire to take care of others
Determination /drive to survive /drive to succeed
Escaping caretaker role in family
Good social organizing skills
Leadership skills
Self-acceptance
Self-reliance
Sense of humor

Table 14. Codes for "What advice would you give to a child living today with a mother who has schizophrenia." (q. 33)

Believe in yourself /know your self worth
Channel your anger into constructive things
Express your feelings/ don't hold it in/ talk with someone you trust
Find another relative to live with / don't stay with your ill mother
Find other people who care about you (i.e. relatives, neighbors)
Get help /get counseling
Have a sense of humor
Keep a positive outlook
Keep a positive self-image
Keep positive relationships with your siblings /support each other
Know that you have a right to be cared for
Make friends /don't isolate yourself
Rely on yourself /trust your instincts and your feelings
Remember that your mother is not equal to her illness /she is a person
Trust your healthy parent /tell them how you feel
Use the arts (music, dance, drawing, etc) to express your feelings

APPENDIX C

Mini-Biographies

Carol

Carol is a warm, friendly woman in her early forties. She lives in Western Pennsylvania with her husband of twenty-three years and an assortment of pets. They have no children by choice. She finished her master's degree in Psychology three years ago and conducts group therapy with adults and research in a psychiatric center. Her husband is a plumbing contractor. She has a large network of friends with whom she socializes frequently. In her group of friends she plays the roles of leader/organizer, counselor and sometimes comedienne.

Carol was born in the United Kingdom in the mid-1960's, the oldest child of three, with a younger brother and sister When she was two, she and her parents moved to a small working-class town in the north of England. They rented a small, but nice house there with a well-tended yard. Her father, William, was a jack-of-all-trades who changed jobs frequently. Among other things he worked as a bookkeeper, a bakery worker, and a cafe manager. Carol's mother, Anne, stayed home with the children with the exception of a brief time as a cashier at the cafe where her husband worked. Carol's brother, John, was born when she was about three. Her sister, Mary, is eight years younger than she is. When Carol was about six, her father got a job as a milkman for a dairy farm and Carol would get up at 4 a.m. with him to accompany him on his early morning milk runs. In her early years, she and her father were inseparable and he took her most everywhere he went. These were mostly happy times for her, although they were soon to end.

Carol’s father’s frequent employment changes and shaky finances caused him to move the family from place to place to escape paying rent to the landlord. When times were tight he would gleefully resort to running cons on people. He would dress up in disguises and use various ploys to trick people out of their money. Sometimes he would have his wife and/or Carol dress up and participate in a scam. Carol felt some qualms about this because she had a strong sense of honesty and knew these cons were wrong. At the same time, she admits that as a kid there was something fun about dressing up and being able to fool people.

Throughout her childhood Carol’s parents argued loudly on an almost daily basis. She never really sought out her siblings for support during their arguments because she was afraid that if they were talking or laughing that their father would spank them or hit them. She felt self-conscious that the neighbors could overhear the loud arguments that sometimes turned physically violent between her parents. Her mother had little self-control and would scream at and hit her husband, or even the children. One time, she broke a guitar over Carol’s back. Another time, she had a board with a nail stuck in the end and she beat her father in the back with it repeatedly until she had torn his back up. Carol helped him clean the wounds while he complained that he knew her mother needed some kind of help but he didn’t know what to do. He complained this way to Carol on many occasions. She felt angry with him for asking her what to do as if she were an adult. She said with indignation, “I was just a kid. *He* was the adult. Why was he asking me?” She wanted him to take charge and do something about her mother.

Carol believes that her mother’s schizophrenia symptoms may have first started around the time when her mother was twenty-three and Carol was about five. She was too young to recognize her behavior as mental illness at the time. She just thought her mother hit everyone because she was angry and mean. Since her father would also hit the children sometimes, her mother's hitting seemed more normal to her, "like that's what parents do."

The neighbors in their small town never reported her parents' fights, Carol says, because domestic violence was nothing unusual there. The main street of their town on the coast of the North Sea was only one street long. The people were somewhat insular and most of the neighbors treated her family like outsiders. The kids at school liked to tease her and her brother because their regional accents were different from theirs. This tended to isolate Carol from peers at school and led to her getting into a number of fights.

Carol described her mother, Anne, as a strikingly beautiful woman. She had graduated from high school and had wanted to be "an air hostess" with the airlines. She had a high opinion of herself and believed she should be, or actually was a movie star, or as Carol said correcting herself, "better than a movie star." She had a nice singing voice, but other than that she had no talent or history to justify her belief that she should be famous. She loved rock-and-roll music and if music was playing, it didn't matter where her mother was or who she was with, but she would get up and start dancing. Carol recalls having many happy times when everyone in the family would sing and dance through the house together. However, she also remembers a constant feeling of "being on eggshells" around her mother because her mother would often hit the children for even minor offenses such as "smacking their food (chewing with their mouths open)." Anne could be nice at times, even generous to people outside the family, but Carol says that if her mother felt you had crossed her in any way, she would immediately lash out at you both verbally and physically.

Anne had a talent for designing and making her own clothes. Her designs tended to be tight, sexy, rock-and–roll style outfits. As a young girl, Carol admired her mother's creative abilities, but she realized as she got older that these outfits were "over the top." They reminded her of the glitzy stage outfits with the shoulder epaulets worn by the singer, Michael Jackson. Her mother liked to dress in these get-ups daily just to walk to the grocery store or to the laundromat. She would parade through the streets in a flaunting sexual manner and then come home and tell her husband provocatively which men in the town had looked at her or propositioned her that day. He didn't seem to care and never objected. This angered Carol because she wanted her father to stop her mother from doing this. Carol recalls that as a teenager she felt intensely embarrassed by her mother's flaunting herself and wished her mother would dress and behave more appropriately. Carol always made sure that her own clothing was more demure to show everyone that she was not like her mother.

Carol felt her father "had no backbone" when it came to controlling her mother. She said:

> He always let her get away with things like she would spend money on clothes (for herself) and all that kind of stuff and we wouldn't have any food, or we (kids) wouldn't have any clothes to wear, and you know it was…(she gets quieter)… I always saw that part of that.

When asked what this meant to her at the time, Carol responded sounding hurt:

> That she didn't like (us) kids. She only cared about clothes, how she looked…I would just be angry inside and then go upstairs and hold it in cause we were never allowed to show our emotions. If we cried that was a weakness and we got smacked for crying and stuff so we just never were allowed to (cry).

Showing how she uses humor to cope with sad emotions, she immediately picked herself up by joking through her gentle tears, “We’re (British) for goodness sake! We don’t do that (show our feelings).”

While her mother had shown notable agitation and aggression at least since Carol was five, Carol feels the full onset of her mother’s schizophrenia was rather sudden and dramatic when her mother was about age twenty-six. This happened shortly after they moved to a town in another region when Carol was eight or nine. Despite being normal weight, her mother had always been obsessive about her weight. Carol remembers that her mother became paranoid that family members were poisoning her food and she would stop eating altogether for days. She became dangerously thin. She was often up all night and she would yell and scream as if she was responding to hearing voices that were persecuting her. She became detached from other family members and would spend hours alone in her bedroom. She would start strange projects and become obsessive about them although she would go about them in a disorganized way. One day she decided to paint the car and used house paint to change the blue car into a two-tone car that was black on the top and yellow on the bottom. Another time, she began pulling all of the wood paneling off the walls and painted religious sayings across the walls. She refused to go in the attic because she said aliens could read her thoughts there. Paranoid about possibly being recognized by imagined persecutors when out in the community, she would often dress up in a nun’s outfit whenever she went out.

Carol is sure that with the screaming at night and the dressing as a nun that the neighbors realized that her mother was mentally ill, but no one really wanted to get involved. Her extended relatives were also aware and didn’t offer any help. Carol says that living with her and her tirades became a living hell. She just wanted someone to come and take her mother away somewhere. Several times her hopes were raised when the neighbors did call the police on her for screaming at night and a psychiatric evaluation team had come to the home. However, during these interviews, Carol says her mother had the ability "to shift" and to suddenly behave normally for the interviewers. She says it was almost like an actor going on stage to perform. She would get a whole different look in her eye and she would hold herself differently and speak in a more conversational tone. The mobile psychiatric team would declare her normal and go away without doing anything or referring her for any services. Carol has always felt extremely angry at the medical establishment for their repeated failures to intervene. She says incredulously:

> Even if she was acting kind of normal with them, couldn't they see the car painted that way and the (religious) slogans painted across the walls!? I mean, do sane people do those kinds of things!?

Almost as soon as the interviewers would leave, her mother would shift back into her angry and detached self. Carol also felt violated by the medical authorities because she had told them the truth about her mother and they did not believe her.

As an adult, Carol has worked through her feelings on her own and she is now able to feel empathy for her mother's plight. However, she still feels angry with her father for his not reacting more strongly to curb her mother's provocative behavior and aggression earlier on. She is also angry at him for his failure to initiate any psychiatric help for her. He would always say, "If I try to make her go to the doctor, she won't go, so what can I do?" Carol feels that instead of helping her mother, her father often made things worse for her. If her father suggested to her mother that she get some help, she would often throw objects, break furniture and/or hit him. Her father would sometimes hit her back and the battle would escalate.

Carol recalls that as a teenager her sister came to her and asked her how she had gotten a scar on her back as she couldn’t remember how she got it. Carol explained to her that when she was about ten and her sister was two, her parents were arguing and her mother came at her father with a knife. As she went to slash him, her father picked up her two-year-old sister and held her between him and the mother to protect himself. As her mother couldn’t stop the knife in time, she cut the baby. Carol doesn’t think her mother wanted to hurt the baby, but that it was a simultaneous thing. Her parents then didn’t take her sister to the doctor, but treated the wound themselves as best they could so they would not get in trouble. Carol says this was a theme with her parents, making the children lie for them to any authorities to cover up their parents’ deficiencies. Carol described that her sister once went truant from school for a long stretch because her father wanted her at home to keep an eye on her mother. Her sister also once had to stay home from school for a time because she had marks on her legs from where her mother had hit her. Her father then coached her sister to lie at the truancy hearing saying she fell on the stairs and hurt her leg and had stayed home from school to recuperate. The case was dismissed in their favor.

Carol feels that her mother’s aggressive behavior was in large part due to the family environment she was raised in. Anne, had been the 4th or 5th child (Carol is not sure which) in a family of 13 children. The family was highly disorganized and personal boundaries were loose. Anne was sexually abused by her father and separately by her brother. Several of her sisters were abused as well. In adulthood, seven of the thirteen including Anne developed schizophrenia-type disorders. Carol feels the sexual abuse was a big contributing factor to her mother becoming mentally ill. In addition, Carol believes that all the rest of her mother's siblings have lesser mental disorders, as do some of their children.

Carol describes her mother's family as “a bad lot” and explains that the family had a reputation around their town for being tough fighters and a bit crazy so that “no one would mess with them.” Carol's mother also demonstrated the family's penchant for fighting. When Carol was about six or seven, she got into a rock throwing fight with some kids down the alley. The mother of the other kids yelled at her and called her mother and yelled at her as well. Carol's mother then started screaming at her and then proceeded to beat her in the head with the high heel of her shoe until the woman's entire face and head were bloody. Her mother then threatened the woman that if she went to the police she'd come back and beat her again. The woman never pressed charges. Carol was traumatized by witnessing this as she felt the incident was her fault because she had been throwing rocks at the other kids. This event was the first that caused Carol to realize that there was something mentally wrong with her mother. Carol feels that her witnessing her mother's violence has influenced her in her adult life to avoid verbal and physical conflicts whenever possible.

In addition to her narcissism, another life-long characteristic of her mother, Carol says, is that she has always judged people based on their looks, especially their hair and their noses. She would constantly criticize other people saying things like, “Oh, would you look at her hair. How can she go out of the house like that, she looks positively a fright.” Or she would point out people's noses as being too big or too pointed. Carol emphasizes that this was restricted to people's looks, never about their character. This gave Carol the impression that her mother was rather superficial.

From early on, Carol's relationship with her mother was ambivalent. She describes her earliest memory of her mother as follows [Interviewer's follow-up questions are in brackets]:

> …When I was about two, I remember being on the cot, like a little metal cot and she was standing over me just looking in the cot…and my Dad was angry. We were in the bedroom and they had been arguing, I guess, (be)cause I could hear the yelling and stuff… I don't know if I was crying or not…but I do remember her looking down... I don't know if she was checking on me to see if I was o.k. or not. [And what are your feelings toward her in that scene?] Hmm, not too good, scared, fear, I guess…[Are you reassured by your mother looking in on you or are you still scared?] …I don't know, it's just strange. I never felt a bond with my mother. I don't know why. I just never felt there was a bond there. And it was almost like a disconnect. I would never call them 'mom' and 'dad.' Even to this day I cannot make myself do it (quiet, sad tone).

Carol feels this "disconnection' from her mother has continued to affect her well into her adult life. She said:

> It has affected me because maybe that's why I feel I have to be around people so much… there's something missing inside (of me) … it's like an emptiness inside and I have to fill it by being around my friends.

She feels that her friends give her a sense of stability and security and allow her to be "more fully (her)self." She is quick to add that this was more pronounced when she was younger and as she has matured she has learned how to be alone and to even enjoy it. Now she's a real "homebody." She goes out with friends because she enjoys it, not because she is trying to fill a void in herself. She credits her husband, Tim, and the sense of stability their marriage gives her as the major factors in her being able to be by herself.

She says, “We talk together. We really talk. And we laugh together all the time.” In the past, she would have never imagined she could be that comfortable with anyone.

As a girl, Carol liked school and excelled there. She received good grades and won several awards. She got along well with her teachers, but does not recall having a special relationship with any particular teacher or even seeking that out. She also could not identify having any substitute parent figure among her relatives or her friends’ parents. Even though she was shy, she still made friends. She had a “big imagination” and this was a great asset in pretend play with her friends. She tended to make friends with children whose parents also had some kind of problem or psychological issue. However, she never discussed her mother’s illness with her friends. When she was out of the house, she never wanted to think about her family or talk about it. She built a mental compartment around it and just wanted to enjoy being with her friends. She never invited her friends to her house even though they would sometimes beg her to have a pajama party at her house, but she would just matter-of-factly tell them that her parents did not allow it and her friends would leave it at that. Her parents also never even gave her a birthday party with her friends, although she said this didn’t really bother her. She just accepted it “as the way things are.”

From the age of about five on, Carol’s parents began giving her the tasks of caring for her younger brother and sister and cleaning the house. They would send her to the store alone sometimes at nine or ten o’clock at night. She recalls holding the money out in her hand for the cashier to count because she didn’t even know how to count money yet. In her parentified role, she feels that she became more of a mom to her brother, John, than their mother was to him. Her baby sister, Mary, remained more attached to their mother. Carol explains that her mother always loved babies (and continues to do so to this day), but once the children became older and had a mind of their own at about age four or five, then she had no more interest in them. Carol does not remember receiving any affection from her mother beyond that age. She also added sadly and with a tinge of anger that her father was an “emotionless man” who showed very little affection, “perhaps an occasional pat on the head if you were lucky.”

Carol did have strong feelings for her pets. Taking care of her pets became the most important relationship to her. She loved her pets because:

> …They’re non-judgmental. They don’t do anything to you. They don’t treat you bad. They just let you hold them and love them and pet them, for the most part. You get to take care of them, you get to train them, things like that, just be with them. There’s no expectations… you come home every day and they’re like, oh, just happy to see you.

She raised a menagerie of small animals through the years including rats, gerbils, birds, rabbits and even a red squirrel. She proudly told how she took her sick rats to the vet to have tumors removed and the vet commented to her that she was the only person who had ever brought him a rat to operate on. He said most other people would just throw the two dollar rat away and buy a new one. Carol could not see how a person could do this. In a strident tone she said that when you take on that pet, you take on a responsibility to love it and care for it no matter what, even if that means spending money at the vet for a surgery. She described how innocent and trusting all of her animals had been. She feels there is nothing better than the unconditional love and affection that her pets have always given to her.

During her teenage years, Carol’s anger and resentment toward both her parents grew. Despite her early caretaking of her brother and sister, her relationships with them felt strained while living in that house. She feels that her father's strictness regarding them not saying anything negative about him or their mother caused the children to suppress their feelings even to each other. Therefore, she does not feel that she and her siblings provided much support for each other. Emotionally, they all stayed in their separate orbits.

By the time Carol turned sixteen, she desperately wanted to get away from home and admits she "needed some structure." So, she joined the British Army and was stationed in Northern Ireland for two years. She says only half-jokingly that dealing with terrorist threats was preferable to dealing with her family. She describes this as mainly a good part of her life where she earned her own money and learned to live on her own for the first time. She made a lot of friends in the army as well as with people in the town. Having friends gave her a sense of safety and belonging. Several of these friendships have been long-lasting. She still stays in touch with friends she met while in Northern Ireland over 25 years ago.

Just after Carol turned 19, she left the British Army and returned home. She found her parents just as intolerable to live with as before she had left. Her mother was delusional and every time Carol would get dressed to go out, her mother would accuse her of "being a prostitute" and "sleeping with sailors." This got under her skin and one night after trying to cool off in her room, she could still hear her mother downstairs yelling at her brother and sister and Carol says she "just snapped." She came down from upstairs with a knife and was heading for her mother in the kitchen. Her father tried to stop her on the stairs and she pushed him down the stairs. He fell to the ground and yelled at her, "Are you on drugs?" With the knife in hand she told her father she was finally going to “get” her mother. When her mother saw her coming, she got her own knife to fight back. Fortunately, her father got up quickly and shoved the dining room door shut between them. Her mother was screaming and kept stabbing her knife into the door trying to stab Carol. When her father finally got Carol out of the room and got her mother to calm down, he realized that if Carol continued living with her mother that there would be a tragedy one way or the other. He then told Carol that he and her mother would leave that night with her younger sister and move somewhere else, leaving her and her then fourteen-year-old brother to live in the house alone. When Carol told her brother, John, the news he was ecstatic. After their parents left, they danced around yelling and laughing. Carol had the song, “The Wicked Witch is Dead” (from The Wizard of Oz) going in her head. Her brother kept asking her gleefully, “They’re gone? They’re really gone?”

Carol and John threw a party the next night and another one a few nights later. Pretty soon their house became “The Party House” for all of their friends and Carol eventually found herself sliding downhill into drinking and minor drug use. Her brother got more deeply into it than her. He had gotten into some trouble before their parents left and he was still on probation. Carol had to go to court with him and she was appointed his legal guardian as their parents were gone. Next, creditors came to the house to repossess their furniture. Carol discovered that while she had been away in the army her parents had taken out loans in her name to buy furniture and had not made any payments. Carol sold the furniture to pay the debt, but it didn’t cover it all. She was prosecuted, but she was able to present proof that she had been out of the country when the purchases were made and that her parents had made the purchases fraudulently in her name. The court wanted to know where he parents were, but Carol couldn't say because her father had never told her where they were going. She and her brother continued living in the house with no furniture and sleeping on the floor on old mattresses. She felt embarrassed by this, but they couldn't afford new furniture. Some time later, she found out that her parents were living in a town nearby, but she and her brother kept their distance, fearing that the parents might try to return to live with them.

In her early love relationships, Carol got involved with men who were controlling and emotionally abusive to her. She said the way they tried to control her reminded her of how her father had treated her. After putting up with the emotional abuse for several relationships, she then resolved to herself that she was "not going to take that kind of crap from anyone ever again." She then met a new boyfriend who seemed nice and they went on a few dates. She decided to test his commitment by inviting him home to the empty house. He was shocked by the lack of furniture and she explained that her mother was mentally ill and that her father had taken her away to live elsewhere. Without saying a word, he just left and never called again. In retrospect, Carol wonders if she might have unconsciously driven him off on purpose to prove to herself her assumption that men cannot be trusted.

A short time later, she met another young man at a friend's party who seemed like a breath of fresh air. They socialized with their group of friends for two months before going on a date. He finally asked her out and she liked that he was very laid back and did not try to control her. She could go out with her girlfriends on a given night without him, and he would tell her to have fun and he'd go out with his friends. She realized after two weeks of dating that she really liked him and was convinced that, "This is the man I'm going to marry." Within a few months, she and Tim were married. She was still only 19 years old and some of her friends warned her that she was being impulsive and that it would not last, but they proved them wrong.

Carol and Tim thought they would settle down in the house that she shared with her brother, however, her parents suddenly returned expecting to live there again. Carol knew that neither she nor her brother could tolerate living with them again, so she called an aunt in another town who agreed to take in her brother and to help him get an apprenticeship. Carol paid his train fare and it worked out well for him. She and Tim decided to immigrate to the United States and in 1985 moved to the southeastern U. S. Tim found work as a commercial plumber and Carol did a variety of odd jobs including hairdresser and veterinarian's assistant. Carol intentionally maintained only sporadic contact with her parents.

At that time, she was not comfortable telling friends that her mother was mentally-ill and often felt the need "to make-up nice things to say" when well-meaning friends would ask about her parents. While she never pursued individual counseling, she began to work through her issues surrounding her mother's schizophrenia by joining a support group for family members of individuals with mental illness. This helped her a great deal in that she realized that she was "not the only one" who had to deal with these circumstances. The group used a lot of humor with each other as a means of bonding and healing their past wounds. She also started volunteering with adults with mental illness. Working with several adults who had schizophrenia helped her to understand it better. She began to understand what aspects of her mother's behavior were caused by the schizophrenia versus what things were due to her own personality. She began to feel more empathy for her mother's plight with her illness.

After ten years in America, Carol and Tim realized that they missed England and Carol felt she might be ready to heal her relationship with her parents, so in 1995 they decided to try going back there again to live. She thought that they could tolerate living with her parents for a couple of months until they found a place of their own. With her new perspective on schizophrenia, Carol also had a notion that she would help her mother get effective psychiatric treatment. However, she says flatly, "That was the worst three months of my life… the childhood was right back there again." Carol had always been open with Tim about her mother having schizophrenia and he had been accepting. But since he had only met them briefly at their wedding ten years earlier, he didn't really know them at all. Before going back, Carol warned him that both her parents would behave rather strangely, but he downplayed this and told her not to worry.

From the moment they got back, Carol says her parents were in their typical negative mode. Their flight had arrived several hours late and her parents in greeting them didn't say anything like, "Oh, I haven't seen you in ten years!" Instead, they complained, "You're late. We made food for you (but) we had to put it in the trash. What the hell do you think you're doing? Blah, blah, blah.." Their negativity went on from there. When Carol and Tim were finally alone, he said to her, "Oh my gosh, I can't believe you come from that family. You are just so different."

Carol learned from her father and sister that her mother, Anne, had made periodic progress with psychiatric treatment since Carol had left England. She had had brief periods of improvement on medication. She had also been helped by several rounds of electro-shock therapy. However, each time Anne would improve for a time, she would think she had gotten all better and would go off her medication. The full-blown symptoms would then return and she would spiral down. This became a cycle. At the time of Carol's return, her mother was back on her medication but seemed to Carol to be "zombied out." The medication made her very quiet and withdrawn. Carol's father and younger sister, Mary, (who had continued to live with her parents well into her 30's), were making most of the decisions for her. They were afraid to let her go out alone and they did not let her answer the phone. They even refused to let her go shopping when Carol asked to take her, even though Anne wanted to go. Anne was able to bathe and dress herself and they were letting her help out with cooking meals. However, they did not trust her to cook alone as they felt she might burn down the house if she was not paying attention. Anne was capable of holding a conversation, but focused mainly on topics in the past. She could stay on the point when discussing things in the past, but when talking about present matters was more tangential. Carol believed that her mother was preoccupied by internal thoughts, but thought that with her medication she was no longer hearing voices. The family had always been Catholic, although they were somewhat lax in their observance. To Carol's surprise, Anne had become devoutly religious and attended Mass every Sunday without fail.

Carol observed that her father had resigned himself to the role of caretaker for her mother. Their marriage had become more like two people just sharing a space together as there was no real emotional relationship between them. She said that her father went through "a lot of really bad things with mom… and he just doesn't have anything anymore… He's just the shell of a man."

Carol saw that her mother retained a childlike way about her. She explained:

> Have you ever met people who just never grew up, who have never reached their emotional maturity? They're still very young and childish? Well, that's my mom. She's never matured. She's like a little girl, if that makes sense?

After moving back Carol tried to reach her mother emotionally by frequently telling her how much she loved her, but her father objected to this:

> She's never heard that (in the family), so I don't care, I'll just say it. So then she's telling me 'I love you, too,' and all that stuff. But then my Dad would just be like he didn't want me coming around and talking about that kind of stuff. He says, 'I don't want you upsetting her' and I'm like, my God, she needs to talk about this stuff. She's carried this on her shoulders all these years. She needs to get out (of the house) and you just won't let her 'cause you're so scared she's going to end up schizophrenic, paranoid crazy, I guess.

Carol and her husband eventually got their own house in England and stayed for ten more years. Tim found plumbing work and Carol pursued some odd jobs. After about four years there, she decided to get more goal directed in her life and applied to the local University. She completed her bachelor's degree in Psychology in 2003, followed by a master's in Psychology in 2005. She continued attending meetings of a support group for family members of the mentally-ill.

Her brother, John, had married some years before and had a baby boy with his wife. However, the relationship did not last and they divorced. This was a big issue with Carol's mother who as a devout Catholic does not believe in divorce. Her railing against John caused him to become more distant from the family. He subsequently remarried and had another child with his new wife. He continued to keep his distance from his parents even though he lived in a nearby town. Carol says sadly that she is close to him due to her having been a substitute mother for him, but he treats her more as a mother than as a sister and so conflicts can occur. She feels that having been forced into this maternal role with him at a young age has cost her a normal sibling relationship with him.

Carol likes her sister, Mary, but has difficulty being close to her due to her lingering resentment of her parents past favoritism of her. She is also upset by how enmeshed Mary is with her parents. Carol doesn't understand why Mary has never moved out of their parent's house and has never been involved in a love relationship. Carol describes her as emotionally immature and thinks that Mary's development has been stunted due to her failure to launch from their parents' home. She believes Mary will never be able to mature until she gets away from them. Carol is encouraged that Mary has been studying for a graduate degree in Education and doing student teaching at a local school. She hopes that once Mary completes her degree, she will move out on her own. Carol understands that Mary may have stayed in the home to try to take care of their mother, but Carol feels she could have never done this. She feels that she had no choice but to leave when she did at sixteen or she would have either killed her mother or lost her own sanity. She has no regrets about having moved away and thinks it probably saved her life.

After Carol got her Master's in 2005, she and her husband Tim decided to move back to the U.S., this time to Western Pennsylvania. Tim got set up as a plumbing contractor and Carol found a job as a group therapist and research assistant at a psychiatric center. They have stuck to their decision to not have children of their own. Despite the fact that she gets along great with children and all of her friends tell her she would be a great parent, Carol feels she could just never be a parent, even if she adopted a child, something she once considered. Her decision she admits is in part about her fear of having a child with schizophrenia, but she explains it is more about her being parentified as a child and feeling like she had lost her own childhood in the process. As an adult she just wants to live her own life with her husband, friends and pets and not be burdened with more parenting. Besides, she says, with her characteristic humor, "If you showed me a photo of a baby and a puppy, nine times out of ten, I would grab the photo of the puppy first and say, 'Oh, how cute!"

At the time of the interview, Carol appears to be quite satisfied with the life she has. She loves her work, has a wonderful close, fun relationship with her husband of twenty-four years, has a large number of good friends she feels she can count on and feels constantly loved and fulfilled by taking care of her pets. She feels she has survived her "crazy childhood" -a mother with schizophrenia, an emotionally unavailable father, corporal punishment from both her parents and being a parentified child. She is able to put it all in perspective despite the fact that she has never had any substitute parent figures in her life, was for the most part unable to use her siblings as a support group while growing up and has never attended any form of counseling (with the exception of the family member's of the mentally ill support groups). While Carol accepts that her experiences have made her who she is, she feels that if she were to go back and change anything, she is a realist and says emphatically that she would "change *the whole thing* not to be brought up like that. I would not want to go back there…not in a million years."

When asked about the main sources of her resilience, without hesitation Carol exclaims, "Pets kept me going! My animals!" Her pets gave her unconditional love and affection and were a vehicle for her to care for something outside herself fully and consistently. In the future she plans to open a private therapy practice with children and to incorporate pets into their treatment. Carol also feels that her intelligence has been an asset as well as her ability to make plans and follow through with them. Even when life in her family was at its worst she always held in mind that it would be a temporary situation. She always had her own “little plans” about getting away and doing things with her life. She feels her stick-to-it-iveness has been vital in her succeeding in getting out of her family situation. Equally important to her has been “denial” and “avoidance.” Carol feels she used these as coping skills as a child to her advantage to compartmentalize the effects of her family and her mother’s illness on herself so that she could carve out mental space for herself to pursue her own development and dreams.

Her husband has also been a long-term source of support to her. She likes that he is “very laid-back and non-judgmental”, and also hard working and reliable. While she initially had trouble in love relationships due to choosing men who were controlling and emotionally abusive, she was able to make a conscious decision for herself that she would “not accept that crap from anyone ever again.” On the basis of this decision, she approached dating with her future husband a bit more carefully and made sure he was not controlling or abusive in any way before committing to him. Twenty-four years later she feels that their marriage is still fun, loving and stable.

Due to her mother’s hyper-religiosity, Carol feels unable to participate in her native Catholicism or any formal religion. However, she does believe in “a Higher Power” and feels it as a positive influence in her life. She talks to God on her own daily.

She feels that friends are very important as well. Her ability to overcome her initial shyness as a child and learn to be an outgoing individual has given her wonderful opportunities to make and keep good friends. In grade school and middle school, she never discussed her mother's schizophrenia with her friends, but being around them served as a means of escape for her, their company being a happy realm, compartmentalized from the chaos her parents created at home. When she was in high school, around age 15 or 16, she and some friends began confiding to each other "how crazy" their mothers were or how they were "cows," but Carol did not make it clear to them that her mother actually had a mental illness. In early adulthood, Carol's friends became true sources of safety and security for her, although she still felt a need to keep a barrier between them and her family issues. It was not until she joined a support group for family members of those with mental illnesses that she no longer felt alone with those issues and was able to open up to others about her mother's illness. She feels talking about it with others has been crucial.

Asked what advice she would give to a child today who is living with a mother who has schizophrenia, she said that the hardest part is being alone as a child and feeling like there is no one to talk to who will understand your situation. She advises that children should call a helpline and get some support or tell a teacher or another adult. She added simply but earnestly that she would tell them, "You have to talk to somebody. You can't live your life without talking to somebody." She feels that this will let them see that there are other people who can help and that care. This would give them the sense that "they're not alone in the world."

Donna

Donna is a 56-year-old grandmother and former nurse living in the Pittsburgh area who has been retired on disability for 15 years. She has multiple medical issues and says cheerfully, “I am a living medical encyclopedia.” In addition to diabetes, she has osteo-arthritis and spinal stenosis. She often has pain in her joints, especially her knees despite having had knee replacement surgery one year ago and consequently needs to use a wheelchair most of the time. In addition, she has battled digestive disorders for many years including Crohn’s disease and colitis that once caused her to lose 60 pounds in 6 months. She has had thyroid issues resulting in a thyroidectomy. Her weight has been a life-long struggle and she opted several years ago for gastric-bypass surgery. This has helped her to keep her weight down, although she notes that this takes away her ability to use food as an emotional coping mechanism. As a result, since the surgery her anxiety and depression have increased. She also has a history of panic attacks dating back to her late teens when she was in nursing school. She currently takes a number of medications for physical pain, high blood pressure and depression. Because her medications cost over $1000 per month, she has taken a part-time job delivering prescriptions for a pharmacy by car in order to obtain prescription drug coverage for herself.

Prior to becoming disabled, Donna worked as a registered nurse for 20 years. She and her husband, Sam, who is a mental health counselor for a social services agency, have been married for 35 years. They have three adult children, Sarah 33, Anthony, 29 and Michelle, 26. Michelle is studying for a degree in nursing and is currently living at home to save money. Neither Sarah nor Michelle are married or have children. Anthony, the middle child, is a machinery technician whose job requires him to travel much of the time. When he is in the Pittsburgh area, he lives at his parents' home. He is divorced and has a young daughter, Katy, 8, who spends weekends with him at Donna's home when he is in town. When he is out of town, Donna and Sam take care of Katy on Sundays as she is court ordered to see her grandparents every Sunday for 6 hours.

Donna was her granddaughter's main caretaker from ages 1 to age 4 because her mother "had some issues," that Donna did not care to discuss. However, when Katy was four, her mother sued for custody and won. Katy's parents get along amicably now, but Donna's contact with Katy is limited to the weekends or to only the Sunday visits if her son is out of town. The limited time with Katy is still painful to her. Until Katy went back to her mother four years ago, Donna had been involved in caretaking and/or parenting children almost non-stop since she herself was five-years-old. At that age, due to her mother's mental illness, she became the main caretaker for her younger siblings. She feels that having no child to take care of now leaves a void in her life and allows her previously submerged depressive feelings to come more to the surface. She also feels depressed regarding her physical limitations which prevent her from doing many of the things she wants to do.

For recreation, Donna's main activity had always been sewing. However, her depression and her arthritis now make it hard for her to get motivated to sew. She is a member of a women's over-50, social group that participates in charitable fund-raising. However, their membership has been dwindling and they are now down to three members. She attends Catholic Church on Sundays when she is able to get there in her electric wheelchair. She explains that her social activities are very limited because for the past few years she has mainly been in “survival mode,” as she put is, coping with her physical ailments and depression.

Donna is the oldest of 5 children, with three brothers and one sister. Donna’s mother, Tamina, was a devout Catholic and her father, George, was a Presbyterian who converted to Catholicism in order to marry her mother. Tamina gave birth to Donna when she was 26. Donna’s earliest memory of her mother is just after her brother was born and in it she feels scared and abandoned at having “lost (her) mother’s attention.” She says this with a tone of sadness and hurt that is still palpable. She describes with anger in her voice how when she was still a young child, her mother turned her into her constant helper with the younger children. Donna says that she, not her mother, was always “the one who had to get the diaper and hold the bottle.” She elaborates:

> It was my job at 5-years-old to keep three little boys younger than me quiet so (my mother) could burn dinner… She wouldn’t do anything in a preparatory sense so dinner was (still) frozen (when she went to cook it). She would be sleeping all day where I would have to watch the kids. So she would be burning dinner and she burnt dinner a lot.

Donna describes that when she was 6, her mother never allowed her to play with the 6-year-old girl who lived across the street because she wanted Donna to constantly watch her younger siblings. Yearning for a friend, Donna invented an imaginary friend to play with and to keep her company.

Each time her mother had a new child, Donna felt she was pushed further and further away from her. She reflects that her earliest memory of her mother (described above) is probably a “composite memory” of the different times her mother had a new baby. When Donna was 6-years-old and her youngest sibling, her sister, was born, she says that she was “practically the mother to the new baby.” Donna describes with her voice breaking how her constantly being in the role of “the doer” for her mother, eventually led her mother to treat her not as an individual child, but as an extension of herself. In telling this, Donna cried in hurt and indignation, before continuing:

> I then took on my grandmother as my mother… my mother died to me. Because I was the doer (around the house), I became a ‘thing’ (to my mother) and that’s where you can see me eating and looking for solace in food … there was no affection (from my mother), affection was gone. I was a thing (begins to cry)…never a person with feelings or needs.

Her mother was always angry and she would constantly scream at everyone. Donna’s father, George, who worked as a television repairman, would escape on Saturday nights with his friends to drink and play cards. “He liked to gamble, he liked to play cards and he liked to drink,” says Donna with no hint of condemnation. She describes him as “an extremely functional alcoholic” who never missed a day of work and retired with full benefits. At home, he would have a beer or two, but Donna never saw him drunk. Donna notes in retrospect, though, that he must have exhibited the behaviors of an alcoholic because consequences of this later became evident in his children. Two of Donna’s brothers became alcoholics and both she and her sister married alcoholics. In regard to her father’s gambling, she says he always set limits on himself so he never lost the rent or the food money. However, when he would come home in the wee hours of Sunday morning, Donna, whose room was next to the front door, could always hear her mother arguing with him as to whether he had been to Mass yet. Her father would lie and say he had gone to Midnight Mass in town earlier that night. Her mother would then ask him where the church bulletin was and when he could not produce the paper, she would start screaming at him. “Why a church fanatic like her,” Donna asks rhetorically, “would marry a Presbyterian (who liked to drink and gamble) is beyond me! It makes no sense.”

Donna’s mother, Tamina, was the 6th or 7th child of 11 children. When Tamina was born her mother did not expect her to live because the baby was hemorrhaging shortly after birth. The family story is that the doctor poured some kind of liquid over the newborn that controlled the bleeding, but he told her mother to concentrate on the other children because, he said, “This baby will likely not live long.” Donna’s grandmother believed this because infant mortality was higher in those days and two of her older siblings had died in infancy. But, Tamina lived and continued being sickly as a child. Whenever she did not feel well her mother always encouraged her to lie down and rest. Her father had an appliance shop on the ground floor of their house and her mother ran a beauty shop in the front room of the first floor. Tamina left school after 6th or 7th grade because her parents felt she was old enough to work and Donna notes this was not uncommon for women in that day. Her mother then sent her to beauty school so she could help her out in her shop. She did help out, but between clients she would always go and lay down. This pattern of having energy only in brief spurts and then needing to lie down at intervals throughout the day continued into her adult life. Donna feels that Tamina needed constant support from her mother or she could not function. However, after she married and moved to the suburbs, she lost the proximity with her mother and her mother’s daily support. Donna feels this was a major stressor to her mother throughout the early years of her marriage.

Although ready to start a family, Tamina doubted whether she could have children. When she had been 16 she had pinworms in one of her ovaries and the ovary was removed. The doctors also removed her appendix at the same time. The ovary removal was a new procedure in those days and the doctors told her there was a 50% chance she could not get pregnant. She also had hypothyroidism and had been put on medication for this. Despite her anxiety, she was soon pregnant, but then lost this first baby. She blamed the miscarriage on her thyroid medication, although the doctors had disagreed with this. When she got pregnant with Donna, she stopped taking her thyroid medication and took a drug possibly called D.E.S. (Donna had trouble remembering the name of the drug) that was often prescribed to women at that time to prevent miscarriage. The birth went smoothly. Being a devout Catholic, she did not believe in birth control and had 4 more successful pregnancies within 6 years. Because she was pregnant more often than not in those years, she was off her thyroid medication for the majority of that time period. Donna feels in retrospect that her mother's unmedicated hypothyroidism probably was a major reason why she was so tired and irritable all the time when Donna and her siblings were young.

Before age 9, Donna did not yet have a sense of her mother having a mental illness, but it was clear that she was not fulfilling her roles as mother and housewife. She was frequently asleep all day and did not clean the house, manage the children or make the meals properly. She didn't give the children baths and she would go off on a tangent and 'beat you to a pulp," according to Donna. She also became hyper-religious and would go to church daily. Donna complains, "She couldn't clean the house, but she could go to church every day!" She also had hundreds of religious medals in boxes and would nail some over every doorway in the house. Donna feels her father would have seen these acts simply as acts of religious devotion if her mother had been doing her job with the house and the kids, but because she was not, he began to see her behavior as irrational.

By Donna's account, her mother did not display clear symptoms of schizophrenia until she was 37-years-old and Donna was nine. It would take two more years before her mother received a diagnosis if schizophrenia by a medical doctor at age 39. Tamina became more and more irrational as time went on. She began reversing day and night and would be up most of the night screaming her prayers aloud, waking the whole house and the neighbors as well. She would scold the children that they were going to hell for only speaking their prayers and not screaming them, as she felt this was the only proper way to pray. Donna's father rebelled against her hyper-religiosity and forbade the children to go to church on Sundays. This set her mother off to no end. Finally, a defining moment came when Tamina told everyone in the family that "red is the devil's color" and collected everything red in the house including drapes, clothing and the red tops of a salt and pepper shaker set that Donna had given to her as a gift. She burned all the red items in a big bonfire in the backyard. Donna's father felt this "burning of the red" clearly showed she had had a nervous breakdown and he sought to hospitalize her. However, Tamina's mother intervened and offered to take her home to her house to live and promised she would get her back on track. Donna says, "Her mother was her therapy. She was going to take her home and help her get her act together." Donna's grandmother settled Tamina into an apartment above her garage and watched over her and so Tamina avoided being hospitalized. Donna's paternal grandmother, at the behest of Donna's father, moved in with the children at their house to help take care of them. (A footnote to the story of "The Burning of the Red" is that as an adult Donna loves to wear red as an act of defiance to her mother. She also has given a piece of her needlework a prominent place on her wall that shows a jubilant dancer who says in a speech bubble, “I will wear red and dance!”).

Donna feels that her paternal grandmother moving into the home provided her with the only time period in her childhood when she was allowed to be just a kid. She says appreciatively:

> I was not in the parenting role… because my grandmother was and I loved it! It was such a relief to have her saying (to my siblings),‘You sit down, and you take a bath,’ and it wasn’t my job (anymore). Not only could I play, but I could just isolate into myself. I didn’t have to be aware (of everything going on) as adults (have to do).

She wished her grandmother would stay with them forever. However, after nine months, her mother and maternal grandmother went to court, sued for custody of the children and won. Donna’s father later told her when she was an adult that her mother’s lawyer had put some social workers on the stand who had never been to their home, but yet these social workers testified that Donna’s mother was a good, responsible parent. Her lawyer downplayed her mental illness as a temporary breakdown from which she had fully recovered. Donna explains that the bias in those days was that the mother would pretty much always get custody of the children no matter what. She adds that the judge who was Catholic wanted the children raised in a Catholic home, which meant they would have to live with their mother. Donna feels that her mother didn’t really want the children back but that her maternal grandmother had pressured her to seek custody so she could then receive alimony and child support money from Donna’s father. The judge did award custody to her mother and Donna felt that her freedom to be a kid had suddenly been stolen away. She was again forced to become the stand-in parent to her siblings.

However, an added twist was that when her father lost custody, he had stopped paying the mortgage on their house, so the house had to be sold. Donna and her siblings had to move with their mother to the cramped apartment over their maternal grandmother's garage.

Donna's parents' divorce was finalized when she was 11. Her father moved nearby and the children got to see him every Sunday. He would take them out to a playground or to the donut shop. He was able to act as a sounding board and a support for Donna and her siblings in the time he spent with them, but his time with them was limited. Despite the limited nature of their contact, Donna felt confident that he would be there if she needed him. She felt very supported by him later when she was going to nursing school and he was always there to pick her up each week and he made sure she had enough money. While he was not an emotionally expressive man, his actions made Donna feel that he cared about her and wanted her to succeed. Donna knew that her father was aware her mother was crazy, but he did not feel it was appropriate to discuss this with her or her siblings until they were over 18. After a few years he remarried, although Donna never became close to her stepmother.

Donna credits her father with always paying his child support and being constantly civil and respectful to her mother. For example, when dropping the children back off at their mother's house on Sundays, he would often buy them a bucket of fried chicken to bring home so their mother would not have to cook dinner that night. Her mother, however, would try to stop everyone from eating the chicken, insisting delusionally that it had been poisoned. Since Donna and her siblings could not reason their mother through this, they would use humor to make their point by taking a bite of the chicken, falling to the floor as if they were poisoned and then laughing to show their mother that they were fine.

Humor only helped the situation so much. Tamina again forced Donna into a parental role with her siblings. Donna says this was extremely hard because at 11-years-old she had no real authority over her siblings the way a parent would so it was hard to get them to respect her. Her mother also tried to push Donna’s brother, George, Jr. into the paternal role, although Donna says “he did not want the job.” Due to space limitations he had to sleep in the same room with his mother and she would often beat him, Donna says, “because he had the same name and looked like my father.” So, Donna and George, Jr. had to struggle on in their undesired roles as substitute parents, although Donna is quick to note that George would rarely cooperate with her, so it was not really a team effort. The only household chore that her mother kept up with was the laundry. Donna says, “Boy, did she love to do laundry! She never stopped.” Her mother tried to save money on water by wringing the laundry out by hand, rinsing it, and then hand wringing it again. She also would not use the clothes dryer and would constantly hang wet laundry all over the house, so that the house was a constant mess of damp clothes.

While their maternal grandmother lived right across the porch from them, she kept her door locked all of the time making it clear that she was not willing to take on the parental role for her daughter. Since Donna’s family had no phone, they would have to go into their grandmother’s house to use hers and her grandmother made it clear that she didn’t like them using her phone. So when Donna was 14 she began selling Avon products door to door and used the money to buy a phone for their apartment and she paid the bill every month. When she was 16, she got a job mopping floors at a local school in addition to continuing to sell the Avon products.

Asked if she ever received any nurturing from her mother, Donna said that her sense is that she did get some nurturing as a baby, that her mother “could manage one child,” but that ended with the birth of her siblings. She got a lot of affection from the family cats, but she wanted it from people. She actively “shopped for it,” as she puts it, from substitute maternal figures. She first got it from her paternal grandmother, and then from her Aunt Millie after her paternal grandmother died and also from a girlfriend’s mother. Unfortunately, all of these substitute maternal relationships were short-lived and the separations when they ended were very hard on her. But, Donna says these relationships were enough for her to somehow internalize good mothering and pass that on to her own children.

Parenting her own children was a struggle, though, for Donna because she had internalized all the negativity she had received from her mother as well. She felt very self-critical of herself, especially regarding her constant battle with her weight. She also had a very hard time “not doing anything.” She felt like she had to be constantly n motion doing things for other people or she was not worthwhile as a person. Several times in the interview, she returned to the point that her mother had turned her into “a thing, not a person.” She says her mother was furious when Donna left home for nursing school and was not there to do all of the things around the house her mother had come to rely on her doing. When she became a parent herself, turning off the internalized negative voice of her mother was exhausting. She did as a parent, however, manage to keep a boundary with her children that she was able to maintain with the help of counseling she received as an adult.

Donna did not want to pass on the internalized negatives of her mother to her own children, because she says the emotional and physical abuse she had received from her mother and her unpredictability had taken a significant toll on her. She elaborates:

> You could label my mother a child abuser because she would beat us mercilessly. She beat my brother, I can remember, a couple of times with two belts in each hand. And when she was in her tirades, she was a powerful force and there was never any logic (to her actions)…

Donna found escape in Science Fiction shows she watched on television such as Star Trek. She especially admired the character, Mr. Spock, because he was the polar opposite of her mother in that his actions were always dictated by logic. She explains [interviewer's question in brackets]:

> Mr. Spock …was one of my mentors because I loved his logic -loved it, memorized it, used it and saw where I was trying to use logic with my mother like with the fried chicken situation (mentioned above) where we could not convince her the food was not poisoned…His logic was probably the salvation of getting me into nursing school and providing me with (a philosophy to live by) …[Interviewer: And the fact that he could master his emotions or suppress them was that a model for you as well?] Yes! Oh, yes (enthusiastically), I felt like that was the way to be.

Adopting Mr. Spock's circumspect, emotionally detached attitude toward her mother, allowed Donna to create a buffer between herself and her mother's illogic. This helped her to never doubt or question her own sense of reality. She always knew that her mother was the crazy one and not herself. She was able to counsel her younger siblings as well when they would start to get caught up in their mother's ravings and ask her why their mother was saying this or doing that. She would tell them in her typical straight-forward manner, “Look she’s crazy. You cannot make sense out of craziness.”

The family isolated itself from the community and the children could only play with each other. Their mother didn’t allow them to have friends or to bring children to the house. Donna didn’t make a friend until she was in high school, although this friend, Jane, was an excellent friend with whom she went on to nursing school and they remained friends for life. But she notes that this was a special case because in general she lacked the skills to make friends because her mother had never allowed her access to peers. This was hard for her even in nursing school when she had gotten away from the family. Later as a mother and grandmother, Donna would go out of her way to make sure her own children and her granddaughter had ample opportunities to make friends and to spend time with them because, she says, that she knows how important this is in life because she, as a child, had missed out on so much.

While neither Donna’s mother or father ever told her explicitly to keep her mother’s issues a secret, Donna while in grade school never told anyone about it. Even though she did not yet recognize her mother’s problems as mental illness, she still knew her issues were “taboo” to talk about. When she got into high school and became best friends with Jane, she eventually confided to her about her mother. Jane was accepting, and this may have even helped to solidify their friendship. Donna also felt support from Jane’s mother and had a good relationship with her. She felt that to be around and to get attention from a mentally healthy adult was very important to her at this time. As the two girls moved through high school, they began planning to escape someplace together after graduation.

Despite her own plans, by the time Donna was a teenager her mother had her life all planned out for her. She was to work at the local Five and Dime store, turn her paycheck over to her mother each week, come home and take care of her siblings and also take care of her mother until she died. After that, Donna was to become a nun. That was Tamina's plan. As a girl, Tamina had wanted to be a nun, but Donna's grandmother had told her it was "a waste of a life" and would not allow it. Tamina now wanted this for Donna, but she also did not want to lose Donna's help in running the household. So, she had come up with this compromise solution that Donna could join the convent later in life. As she viewed Donna as an appendage of herself, it was irrelevant to her what Donna wanted to do with her life.

After graduating high school, Donna's simple aspiration was to become a mother and a housewife. However, she explains that she was overweight and was stood up for the senior prom, so her prospects with men did not seem very good to her. When her friend, Jane, became interested in going to nursing school, Donna jumped on the idea with her. Donna did not so much want to be a nurse, but wanted "to run away from home and be safe," she says, She wanted to live in the nurse's dormitory where there was a house mother "who protected you," unlike her own mother. She was, however, required to bring her mother to the admission interview and Donna told the interviewer quite bluntly that because the family was on welfare that if the school accepted her, they would have to give her a full scholarship for the whole time she would be enrolled. Her mother began to scold her for being rude to the interviewer. However, the interviewer liked Donna's assertiveness and offered her a full scholarship on the spot.

Reflecting her hunger for order in her life, Donna painstakingly prepared her belongings to bring to the nurse's dorm, from making sure she had enough towels to buying band-aids and other minor sundries. Her father bought her the big ticket items of a hair dryer and an alarm clock and she felt touched at having received such gifts noting that, "It wasn't even my birthday." Once in the dorm, she realized that her great preparations had given her an entrepreneurial opportunity. If someone needed a band-aid or a tube of toothpaste, they came to Donna. She soon began operating an informal store out of her room to make extra spending money. She needed this because even though Welfare had given her mother an extra stipend for Donna's nursing school expenses, her mother had kept the money.

Donna had a hard time transitioning into nursing school. She had trouble making new friends, although she still had Jane, her best friend from high school who was living across the hall. But, the separation from her family was hard, especially the worry she felt about how the younger ones were doing. At the start of winter, she became agitated when she discovered that the hot water and heat had been out at her mother's apartment for several days and that neither her mother nor her grandmother was doing anything about it. Donna ran right over and scoured the newspaper ads trying to find them another apartment, but her mother kept trying to foil her efforts by telling her no one was going to rent to a mother on welfare with four kids and by running the vacuum to disrupt Donna every time was on the phone with a potential landlord. She says clearly her mother did not want to leave her grandmother's house even if it meant her and the children freezing to death. Donna felt horrible for the children and says angrily that if it had happened today, social services would have come in and removed them. At the dorm, Donna got more and more depressed, began over-eating and put on a lot of weight. The school intervened, and the doctor gave her “a big bottle of lithium” to relieve her agitation. The nurse later took the bottle away thinking she might try to overdose on the pills and instead she administered Donna’s medications to her daily. Her friend, Jane, said that each time she came to Donna’s room that she half-expected to find her hanging from the ceiling pipes. Eventually, Donna arranged for the heat to be fixed at her mother’s apartment and she was able to calm down and focus on her work again.

Despite her fragile emotional state, she still made good grades, although she almost flunked psychiatric nursing, a course which she feels raised a lot of personal issues for her she was not ready to face. She felt this had contributed to her poor mental state. When she read about schizophrenia in her textbook, she knew this was what her mother had and wanted to help her get treatment. She showed her aunt and maternal grandmother her textbook and tried to convince them that her mother had schizophrenia, but they told her flatly, “No, she doesn’t have that.” Donna found their denial infuriating because she felt that without their agreement she could not get her mother the help she needed.

When faced in her training with a client with schizophrenia, she did not know how to deal with the woman and just wanted to get away. When she took her boards she “got nationals” in every course but psychology. She felt stumped by the multiple choice questions of the appropriate way to talk to a person with schizophrenia. Based on her experience with her mother, she felt that “there was no point” in trying to talk to a person with schizophrenia because they could not respond to anyone in a rational way. Her sense of schizophrenia was that this was a permanent disorder and that there was no way to rehabilitate the person. When her training moved on to surgical procedures, she felt quite relieved because this was material that was logical and factual. She felt much safer studying this type of material.

After graduating from nursing school, Donna rented a three room apartment for herself. She had earlier promised her younger sister, that once she had her own place her sister could move in with her. However, when she proposed this, her sister said she preferred to get her own apartment. Donna got a loan so that her sister could buy furniture for herself and her sister moved out on her own. A year later, Donna had started dating her landlady's son, Sam, who had his own apartment in another building. Donna says the two of them "just clicked." Sam was charming and amusing, with a great sense of humor, "the Tom Hanks of his time" as she put it. He was quite emotionally sensitive as well and she made the observation that most comedians use humor effectively to mask their emotional pain. She was open with Sam about her mother having a mental illness and he confided to her that his mother, having been put into a concentration camp in Nazi Germany during World War II at the age 16, had some mental health issues as well. They bonded over their shared experience of having a mentally-ill mother. They were soon engaged and set a date on a Saturday night, three days before Christmas. Donna, ever resourceful, catered the food herself. However, her mother gave her a hard time telling her that she could not get married on a Saturday night, three days before Christmas. Donna told her bluntly that this was exactly what she was going to do and that if her mother did not want to attend, then she didn't need to come. The wedding then went off well with her mother in attendance.

Sam and Donna moved into her apartment in the building that his mother owned. They eventually bought the house from his mother and they continue to live there to this day. Sam's brother and his wife lived in the apartment upstairs and were raising their two young daughters there when Donna and Sam were first married. Donna says she loved how Sam played with, talked with and helped take care of his toddler niece and how he would change the diaper of the infant as well in a day when men didn't usually do that. This reassured her that he would make an excellent father and that if she had any deficiencies as a mother as a result of her upbringing, that he would be able to offset her. They had their first child, Sarah, when Donna was 26.

Donna had a terrible time medically during her pregnancy with Sarah. She had hyperthyroidism and was unable to sleep. At one point she had not slept for three weeks straight, yet miraculously did not become psychotic. Toward the end of the pregnancy in late August, she was put on a medication so she could sleep, but she had gained over 100 pounds and was very depressed. Sarah was born by Caesarian section in the fall. By Christmas, Donna was feeling suicidal, went to the hospital for an evaluation and was put into outpatient counseling.

Parenting was initially difficult for Donna due to her struggle with her anger about having been a parentified child. This was complicated by the fact that Sarah had some social learning difficulty, although this was undiagnosed at the time. Without an understanding that her daughter had special needs, Donna would often lose patience with her and yell at her. When Anthony was born four years later, and Michelle three years after him, they did not have the same issues as Sarah. Donna then realized that Sarah's social deficits had contributed to her difficulty managing her. Based on her own lack of having been allowed to be a child and to have friends, Donna always made sure that her children had ample opportunities for play and socializing with peers. She encouraged them to bring friends over for sleepovers. She taught them responsibility by giving them small chores that were age appropriate, such as having her five-old-daughter sort the silverware from the dishwasher. She says, "I wanted them to be kids, so I shielded them from the trenches. Their job was simply to go to school and to do their homework and their little chores." She continued this philosophy in helping to raise her granddaughter.

Because of the beatings Donna had received from her mother as a child, she was always careful to only use corporal punishment with her children on the rare occasions when they had put themselves in danger and she wanted to make a strong impression on them. For example, when Sarah was 13, she went downtown with her friend on the bus at night without permission to a dangerous area to walk the streets. On another occasion, Anthony lit a fire underneath the gas tank of their car. These types of incidents were the only ones where she ever spanked her children.

Donna also recognizes that there are echoes of her relationship with her mother in the marital relationship. She describes herself as very much "the parent" and the manager of the home. She says the things she loves about her husband –his easygoing nature and fun-loving, playfulness—are also the things she hates about him. She hates that she has had to be the disciplinarian with the children because he is so "reluctant to be the heavy." She also dislikes having to be the one to tell her husband to clean up his things. Mainly, she resents the times when she feels that she is in a parental relationship to him. She feels this reawakens her anger at having been a parentified child and this, she feels, contributes to a sense of distance in the marriage. She wishes there was more demonstrative caring and physical affection between her and her husband. She notes that they have been through some tribulations such as a time period early in their marriage when he was drinking, but when Donna made a stand and said, “This is not acceptable,” he responded well and joined AA . He has now been sober for 27 years. She somewhat reluctantly agrees that the marriage is “a success” and says, “After 35 years where am I going?!” She continues to hold hope that the marriage will get even better.

As a woman now in her 50’s, however, Donna resents the fact that she is still contending with “the ghost” of her mother (her mother is still living) that she has internalized and that this continues to enter her current life and relationships. Donna cannot just let herself “be,” because she continues to define herself as her mother’s “doer,” that is, in terms of what she does and what she can’t do for other people. Her physical disabilities are extremely hard for her in this regard, because she can no longer slip into her comfortable “doing for others” mode to hold off her depressive feelings.

Donna first became disabled at age 40 when she had a parathyroid tumor in her neck and the parathyroid was removed. Following the surgery she couldn’t read and she couldn’t do math. She says, “Here I am a registered nurse, and I can’t tell if I have the right change from my dollar?!” Despite these focal cognitive deficits persisting into her fifties, when one speaks with her, her conversation is on the point and her logical reasoning skills still seem quite sharp. Even though she often feels despair regarding her deficits, when her husband and adult daughter enter the room briefly and she gives them gentle, but firm directives, one gets the impression that she is still very much the central organizer of the family. Even though her limitations make her feel depressed, at the same time her love of her family and belief in God continue to give her hope.

Donna maintains a sense of spirituality and “belief in God and Jesus”, but feels she cannot give herself over fully to formal church because she resents how she had to contend with her mother’s religious fanaticism (i.e. her screaming of her prayers at night) as a child. In contrast to her mother’s demonstrativeness, Donna’s religious outlook is full of humility. She says:

> I think (praying) should be quiet. You should go in a room and shut the door just like it says so in the Bible. You shouldn’t scream your prayers and if you’re going to fast you should do so with your hair combed and your face washed and a smile on your face. And don’t let people know that you’re fasting…and just be good to other people—whatever goes around comes around. Do things for other people without getting any payment. If you get payment, it doesn’t count.

She accepts the fact, though, that the morality she has learned because of her mother’s exposing her to formal religion has kept her on a straight course throughout her life, although it bequeaths a set of fears as well. She continued:

> I’m sort of afraid I’m going to hell because she (my mother) said it so many times (to me) and that is why I have to be so perfectly good. I can’t break any of the big rules. I have to be honest to a blemish.

Donna identifies her main supports in childhood as her paternal grandmother, her Aunt Millie, her one good friend, Jane, whom she has had for life, Jane’s mother and her cats. She also had a dog for part of her childhood, but she feels that she got more affection from the cats. While she did not see her father on a daily basis, she feels that she always had his approval and support which was important to her. She also found that taking care of her younger sister as a child fulfilled her. Donna explains that:

> When you take care of somebody and you can see that they are thriving because you’re taking care of them, that’s a response of positiveness, I would say.

She also feels that Mr. Spock, although a fictitious character from television, was a real source of support to her as the method of logic she learned from him helped her to buffer herself against her mother's illogical rages.

Donna feels her sibling group growing up was not that cohesive, but that she and her brothers would always band together to protect their younger sister. She says they would all physically stand in their mother's way if she ever tried to hit the little one. Donna says, "My brother, George, took most of the brunt of the beatings and he has, I would think, the most problems (now as an adult)." Donna feels that being a nurse, she has sought out the most counseling of her siblings. She feels that the group counseling she attended was "not helpful on any point." She felt helped by individual counseling when she was raising her children because it provided her with some parenting guidance and it was a good outlet for venting. She is saddened that her younger sister continues to blame her for some of her problems. Donna feels these are not her fault. This especially hurts Donna because she raised her sister, got her out of the house, and helped her to raise her children when they were young. She feels she has always been there for her, but because she was more like her sister's mother in childhood than her sister, that their relationship carries the pitfalls of all parent/child relationships. At the time of this interview, they had not spoken for three years until Donna took the initiative to reconcile with her last Christmas. The relationship is still a little touch and go, however.

Asked how her relationship with her mother has changed over time, Donna describes how in childhood she was an extension of her mother—"a human doing," as she phrased it-- whose job was "to make (her) mother's life more manageable." As a young adult, this changed to being a separate person, but continuing to be an outside caretaker of her mother's affairs. In middle adulthood, she became a direct caretaker when her mother moved in with her and her husband for two years following an in-patient hospitalization. And finally, a few years ago, Donna virtually cut all ties with her. She says tersely, "She's a very sick woman." After a pause, she continues:

> When she reported me to (The Department of) the Aging and they were going to arrest me …because I was the payee of her social security payments and she thought there should be more money in her monthly check… that was the absolute cat's meow. That was the last straw. I do not feel responsible for her in any way, shape or form. I'm done. I've done my duty. I did seventeen years worth of duty and I did another year or two there when I took care of her in my home and that's it. I'm done.

Asked what she would tell her mother about her childhood experience if her mother could understand this, Donna said she *has* told her mother about her childhood experience and her mother has said adamantly, "I did a good job" and does not want to hear anything to the contrary. But upon a second request for Donna to think of what she would really say to her mother, she became quite tearful and said haltingly through angry sobs:

> I wanted to be a person. I am a person! I'm a person now! I'm not a thing that was there and left for nursing school to make your life more miserable. I'm not a thing, I'm a person! (sobs) And all of your (religious) statues, they're things, not people (cries quietly).[Interviewer: So it's not just the anger, it's a lot of hurt (that you feel)?] Sure, a lot of hurt. A person should have a mother (getting louder, angry tone) and if she couldn't be a mother, all the people around us lied, and lied in court that she was a mother. But, she wasn't a mother! And we all should have been given to other people to raise us.

Asked what advice she would give to a child today who is living with a mother who has schizophrenia, Donna's first response was, "Run away!" She then gave a more considered response:

> …It would all be a matter of if the mother is taking her medicine or something and even then they don't take their medicine, none of them do. I would encourage the child to go live with an aunt or an uncle…As far as I'm concerned you should take all the schizophrenic people and kill them and if you don't want to kill them then they should be given those shots that they have now where once a week they track them down and give them a shot and that should be an absolute court-ordered thing by law.

The violence that Donna advocates here is uncharacteristic of her. It seems to be a statement that reflects her feelings of anger toward her mother for her inability to have been a functional parent. This anger has now persisted into Donna's mid-fifties. She berated herself for not yet having resolved this anger, prompting her to ask herself out loud, "My gosh, I'm a woman in my fifties now, am I ever going to be over this!?"

Donna has worried extensively that "the ghost" of her mother will filter through her down to her children and also affect them negatively. She has therefore been scrupulous about monitoring her own interactions with them. Just as she sought as a child to buffer her younger sister from her mother's blows by taking the blows herself, Donna has kept herself between her children and harm's way. She has shielded them from having any concerns for adult matters such as the finances of the household. Her protectiveness now extends to her granddaughter as well. She continually explains to her son, that the main thing his daughter wants from him, is for him "to be there with her in a loving, attentive way." She realizes that friendships with peers are crucial to children and regularly arranges for her granddaughter to have a friend visit with her when she spends weekends at her home. She has made sure that her children and her granddaughter have had proper childhoods. She is very much the protective momma bear of her brood and has somehow developed the ability to do this in the absence of a functional mother while growing up.

Asked if she would ever want to live that childhood again, she answers in a defiant tone, “Not in a million years!” But, after a pause she added, “Although it did make me who I am.”

Robin

Robin is a forty-year-old woman who moved to the Pittsburgh area three years ago from Florida. She works for a major hospital as an in-home, therapeutic support staff with children who have behavioral disorders. She is single and lives in an apartment with her two cats. She is not currently involved in a romantic relationship and has no children. Robin has a best friend, Diane. Robin enjoys going out with Diane and her husband on weekends to play darts or to shoot pool. Robin’s other interests are reading fiction and gardening.

Robin was born in Florida in the late 1960s, the youngest of three sisters. Her parents, Annette and Bill, were both from Italian-American, Roman Catholic families and were both born and raised in the suburbs of New York City. Robin’s mother Annette, after finishing high school, worked at a bank. While there, she met Robin’s father, a police officer who walked the beat in that precinct. They began dating and were married in New York in the mid-1950s when she was 20-years-old. Bill disliked being on foot patrol in the cold winters of New York and convinced his new wife that they should move to a warmer climate. They first considered California, but then Annette suggested Florida. With unusual foresight, she argued that when they retired, they and their future children would already be living in Florida and thus they would not need to move away from the children.

In Florida, Annette and Bill, tried to have children right away, but after seven years, Annette had still not gotten pregnant. They began looking to adopt, but then Annette was suddenly pregnant with Robin’s oldest sister, Pam. She was born when Annette was 28. They went on to have Robin’s sister, Jeanine, five years later and then Robin, two years after that. Robin’s father continued to work as a police officer in Florida and her mother stayed home to take care of the girls. Robin thinks that because her mother came of age in the 1950’s that once she started having a family she would have no longer thought about working outside the home.

Robin remembers that when she was very young, her mother seemed like a perfectly normal mom. When asked to describe her, she immediately responded, “Fun!” Her mother liked to joke around and dance and do things with the two older girls. She liked to sew and she made most of the girls’ clothes. Robin notes, however, that she herself did not learn to talk until she was four-years-old. She feels this may have been due in part to having two older sisters who would anticipate her needs before she even asked. But, Robin’s theory is that her language was delayed because her mother had given her little individual attention as a toddler. Robin recalls being put in a playpen “all the time” until she was at least four. She thinks her mother kept her in there so that she could sew or do things with her older sisters. An oft-told family story is that when Robin was a toddler, she once wanted a banana, so her mother tried to get her to say “banana.” When Robin didn’t say it on the first try, her mother immediately gave her the banana anyway. Adult Robin, trained as a pre-school teacher, wonders if this story illustrates her mother’s general lack of effort with her when she was small. She does not feel that she ever got enough one-on-one attention, interaction or physical affection from her mother. She adds that “there were some hugs, but not a lot.”

Robin believes that this lack of having her mother fully present with her in her early, formative years caused her to become a very fearful and anxious child. She developed many irrational fears such as if she did not keep her blanket all the way up to her neck while in bed, a stranger would break into the house and steal her. Another example of her mother not tuning in to her was when Robin had her first period when she was about twelve. Robin was very frightened at seeing she was bleeding and had no idea what was happening to her. She ran to her mother and without any fanfare or explanation, her mother simply handed her a pad and told her to go use it.

Robin did get attention from her father when he was home. As she was the youngest, her father even doted on her. However, because he had a second job moonlighting as a security guard, he was usually at work until long after she went to bed, so she seldom saw him. Her father’s main job as a police officer trained him to separate himself from his emotions, and Robin feels this carried over into him submerging his emotions around the family as well. Thus, Robin feels that neither parent really taught her how to communicate her feelings or how to deal with them. Her interactions with her sisters were typically antagonistic so she did not feel close to either one. She can’t recall them ever discussing their feelings about anything with each other, much less their mother’s mental illness.

Robin never really developed any special relationships with any substitute adult figure for her mother with whom she could share her feelings. When Robin first started school, she had difficulty learning to read. She remembers how her second grade teacher put a great deal of time and effort into helping her to read. While the extra attention made her feel special, she never shared her feelings with the teacher. It did make her want to become a teacher herself one day, a dream she later fulfilled. However, other than this one instance, she never developed any special relationships with teachers or adults outside the home.

Robin’s mother first started showing signs of schizophrenia when Robin was about nine-years-old and her mother was forty-three. Until she was nine, Robin recalls that at least to outward appearances her mother was a perfectly functional mother. She cooked the meals, cleaned the house, did the laundry and drove the kids to wherever they needed to go. She was actively involved with her sisters and served as the leader of their Girl Scout troop. Robin can recall isolated times when her mother was responsive to her individually, such as when Robin said she liked mommy’s new ‘Dorothy Hamill’ style hairdo and her mother took her straight to the hair salon to get Robin’s hair cut the same way. But other than a few times such as this, she felt that her mother mostly ignored her.

Robin feels that the main emotional issue for her has always been that there was something fundamentally missing in her early relationship and interactions with her mother. She was constantly trying in vain to get her mother’s attention and acknowledgement that she was loved and valued. She elaborates:

> I always tried to earn her respect, always, always. I mean literally, she would tell me to do something and I would try to do it in order to please her and try to gain that respect and try to get some validity out of my life.

Despite Robin’s constant longing for her mother’s acknowledgement, there was at least a sense of normalcy in the home before Robin was nine. Her parents were active in their Catholic church where her mother played the organ at Mass and her father acted in church plays and pageants. Robin recalls the time her father played Pontius Pilate in an Easter pageant and she and her sisters were in the crowd yelling, “Crucify him!” While they knew it was inappropriate, they couldn’t refrain from giggling because it felt strange that the man playing Pilate was their father.

In those early years, her parents seemed to have a good relationship with each other and went out together every Saturday night. Robin recalls a time when she was five or six that she was watching her mother put on her make-up to go out and her mother asked her what she wanted to be when she grew up. Robin responded, “I’m going to be your mommy.” In telling this, adult Robin, realized that her response probably reflected some separation anxiety and her wish to keep her mother with her forever, but at the same time, with gallows humor she added, “ I doomed myself because I (later) did become her caretaker.”

Even though family life was normal on the surface, Robin’s fears and anxieties kept her in a state of inner turmoil. She had chronic stomach aches and trouble sleeping. She was shy in relating to peers, so she invented an imaginary friend. Her mother did not make herself available to her to reassure her or to allay her anxieties. Her sisters teased her for being a hypochondriac. Robin’s reality was that she felt afraid almost all of the time. She learned to escape into reading books, all kinds of books, but mostly fiction. She earned money through babysitting jobs so she could keep on buying more books. As long as her mind could escape into the alternate reality of a book, she did not have to focus on her own family situation and her own anxieties.

As Robin got to be ten or eleven, it became clear to her that her mother played favorites among the girls. Since her oldest sister, Pam, was by then a teenager and out with her friends most of the time, her mother pretty much left her alone. However, Pam always missed her curfew and then her mother would beat her with a yardstick. Neither, Jeanine, the middle sister, or Robin ever got hit with this; it was reserved for Pam. Her mother also decided that certain things would be reserved for Robin and Jeanine too. Jeanine would be the princess and nothing would be required of her in terms of chores, but it would be her job to keep her mother company at the all-night breakfast place at 4 or 5 a.m. when her mother couldn't sleep. She cast Robin into the role of servant. Robin says:

> Every spaghetti night, my mother would leave that big dirty sauce pot for me to scour. I remember scrubbing and scrubbing that thing trying to get it clean. And it never was Jeanine's turn and if I (complained) about it out loud, then my mother would come and slap me in the back. She used to wear this big amethyst ring and that would hurt when she hit me with it on. I mean I wasn't really hurt, but it was the shock of it because you would have no warning it was coming.

Her mother also expected Robin to treat Jeanine with the same privileged status that she accorded to her:

> Jeanine would be lying on the couch and she would suddenly demand, "Get me a glass of water!" And I would be like, get your own water! Then my mother would scream at me, "Go and get your sister a glass of water!" She never told her to go get it herself, and she never told Jeanine to get me anything.

Her mother was always on her case and nothing she did was ever good enough. As a way of coping with the situation, Robin tried to stay out of the home as much as possible. She remembers going for long bike rides alone. She also developed competencies that could consistently get her out of the house, such as babysitting. She became a sought-after sitter in her neighborhood and babysat almost every weekend night. This allowed her to see other families and their home lives. She saw that the other parents actually seemed to like their kids and spoke to them affectionately. This is when she began to realize that there was something important lacking in her own home life with her mother.

Also, around this time when Robin was nine, she could feel that tensions between her parents were building. Robin’s father had resumed doing night patrols and this increased her parents’ marital conflict. She feels this was mainly due to her mother being paranoid to be home alone at night while her father was out working. Her parents’ arguments became more frequent and intense and her father began drinking more. One night, he got a DUI and a stiff fine for smashing into five parked cars belonging to their neighbors. A short time later, he announced that the family was moving to a new two bedroom townhouse. He said that Pam and Jeannine would share one bedroom and that Robin and her mother would share the other. Robin asked where her father would sleep and without explanation he said that he would have his own apartment. Neither he nor her mother said anything else about the arrangement or the fact that they were separating. Robin later learned that her mother had requested the separation.

Robin and her sisters continued living with their mother and they saw their father on weekends. He never remarried. Needing income, her mother got a job at a department store as a clothing buyer. She was able to hold this job for about three years until Robin was in the 7th grade, although Robin notes that if the hours had not been flexible her mother would have never made it through a month as her mother could not keep herself on any regular sleep schedule. Her mother also made extra money at night, using her musical talent to teach people how to play the organ.

Despite being able to hold a job and give music lessons, Robin's mother first began showing signs of mental illness in the months following her separation from Robin's father. Annette would be up late at night at three or four in the morning banging cabinets and yelling at people who were not there. She would also yell and curse at people who called on the phone or would argue with the dial-tone as is a person was there. She became interested in astrology and began trying to create people's charts. She then began doing "automatic writing," claiming that spirits of the dead were coming to her and dictating their writings through her. At first, Annette said these spirits were just average people, but later on, she began claiming that famous people were communicating through her. Robin has never read any of her writings, but her sister later read them as an adult and told her that their mother would change penmanships for different people and that some of the early writings were "beautiful" in a literary sense. As Annette's psychosis became worse, the volume of her writings decreased and they no longer made any sense.

For Robin as a nine-year-old, the idea that spirits of the dead were coming and going from the house scared her out of her wits. This added to her load of fears and anxieties. While she knew her mother "was crazy," Robin was still always bothered by "that small doubt" that maybe some of what her mother was telling her was true. Her mother repeatedly told her as a point of fact that she could see and talk with these dead spirits—and that these spirits were coming in and out of their shared bedroom all night. This is what Robin observed when she peeked out from under her covers:

> I would wake up at two in the morning and my mother would be writing (dictations from dead spirits) at her desk. I would wake up at four in the morning and my mother would be writing at her desk… or else she would be yelling and

> screaming at someone who wasn't there or else banging cabinets and doors in anger in the middle of the night.

However, to this day, Robin continues to have a primed fear reaction if she hears any unusual noise in the house late at night because she has internalized "that small doubt" that maybe what her mother told her about the spirits is real.

In retrospect, Robin finds it strange how her mother was able to be "so crazy" at home, but still able to go to work and do her job for several years. She notes that her mother had the ability "to pop in and out of reality." If her mother had to talk to one of Robin's teachers or a neighbor she could seem perfectly normal, but then the minute she got home, she would lock herself in her room and resume her automatic writing, often to the exclusion of all else. When Robin's older sisters would sometimes chase Robin through the house, she would yell for her mother but her mother would just stay in her room with the door closed and not help her. Sometimes at meals her mother would be staring off into space for a long time, then suddenly snap back into reality to give Robin a chore or a reprimand.

Robin feels that she and her sisters did not band together to give each other support, but stayed in their separate orbits in dealing with their mother's illness. When Robin was about ten, her oldest sister Pam was about sixteen and had a car, so she was usually out with her friends pursuing what Robin called her "marijuana and quaalude-hazed existence." Robin and Jeanine were usually in the house with their mother, but they were not close because of the differential treatment they received from her. Robin was very envious of Jeanine's privileged status as her mother's favorite and this interfered with the two sisters being friends.

As time went on, Annette's delusions increased. She claimed that she was Jesus Christ or "the son of Jesus Christ." She made predictions about the future such as that when she would die, she would come back from the dead and "time would run backwards for seven years." She would tell the children often that they should be nice to her because "(she was) coming back" after she died. Once, when Robin's oldest sister, Pam, brought some of her teenage friends home, her mother decided these teenagers were "the descendants of the disciples." Some of the teenagers played along with her, but Robin says as this was 1978-79, the kids were smoking marijuana and doing quaaludes in the back yard. Since they were high, they might have agreed with anything, or they likely just went along with whatever her mother said, so that they could continue doing drugs at their house. Despite her mother's florid delusions, she was never hospitalized psychiatrically, nor did she ever see any doctor or take any psychotropic medication.

In contrast to Pam, Robin never invited any friends home. She says strongly, "Why would I want to invite my friends into my anxiety-ridden, fear-ridden existence?! I would much rather go to their houses where life was at least more normal." She never said anything to friends or teachers at school about her mother being mentally ill. Her best friend from 4th grade only learned about her mother's illness in later adulthood. Upon hearing this from Robin, she said, "Wow, I had no clue."

Robin's rejection by her mother and her mother's favoritism of her sister, Jeanine, were underlined further when Robin was about 14. Her mother needed to move to a new apartment and she could only afford a two bedroom. She didn't want anyone to have to share a room anymore. Robin's oldest sister, Pam, was out on her own at this point. So her mother decided that she and Jeanine would live together in the two-bedroom and that

Robin should go live with her father. Robin felt very hurt by this forced separation because all she ever wanted was for her mother to like her and to be proud of her, and all she ever got in return was rejection. Robin then lived with her father for most of high school, the three years from ages 14-17. For a long time after moving in, she was unable to fall asleep at night because the house was too quiet. Robin found that she had become habituated to her mother's noises in the night. She now realized that most people's houses are quiet at night when they sleep and that her mother's noisy house had been an aberration.

At her father's house, Robin was able to relax. "I was free (of my mother) then for the first time in my life." Robin immersed herself in school and was able to successfully compartmentalize her family life from her school life. She was, at least on the surface, one of the happiest kids there. People would say that if Robin didn't have a big smile on her face that there must be something really wrong. But, she explains that she unwittingly cut her happy period short because she continued to crave affirmation from her mother. She says solemnly, "I went back to live with my mother when I was seventeen. Jeanine was moving out to her own place and I was still *so* locked in on trying to get my mom's approval that I went back." She soon regretted this decision as things with her mother were the same as before.

Robin finished high school with decent grades and graduated with her class in the mid-1980's. She applied to some four-year colleges and was accepted at a small liberal arts school in Georgia. The acceptance letter made her feel like, "Finally, somebody wants me!" However, her father told her they could not afford the tuition. No one at home or in school had ever told her about financial aid as a possibility, so she had not even considered this as a way to pay for school. Instead, she continued living at home with her mother and earned an associates degree in Early Childhood Education from the local community college.

Around this time, Robin's sister, Jeanine, wrote her mother a letter announcing that she was gay. Being a devout Catholic, her mother took this news hard. But, instead of being upset with Jeanine, her favored child, she instead went after her usual scapegoat and blamed Robin for the fact that her sister was gay. This did not help Robin's relationship with Jeanine, whom she already resented for moving away and leaving her to take care of their mother alone.

After Robin graduated from community college when she was twenty-two, she suggested to her mother that they move to the Tampa area as they had both always liked it. Her mother suggested instead that they move to North Carolina even though they didn't know anyone there. Annette argued that since it was geographically between New York and Florida, that it would be easier to visit family in both places. (Robin explains that her mother's plan had always been to move back to New York City and that this move also represented her mother's attempt to get closer to New York). So, they moved to North Carolina and her older sister, Pam, her husband and new baby relocated with them and lived with them for the first six months of the baby's life. Her mother got a job as a cashier at a supermarket and Robin worked as a preschool teacher. Robin also helped her sister take care of her baby.

About the same time that Pam and her family moved out to their own place, Annette became unable to go back to work. First, she stopped driving and then she stopped going out of the house altogether. Her paranoia became worse. Robin began to act in full as her mother's caretaker. She says:

> I now knew what my life would be. It was all planned--supermarket, cigarettes, mom--supermarket, cigarettes, mom-- me going to work--supermarket, cigarettes, mom.

Robin became depressed herself, or at least realized it for the first time. She says that really she had been depressed her whole life and it had just felt normal to her. She was able to have energy whenever she was teaching the children at school, but as soon as she would get home, she would feel depressed again. Her mother not only kept her busy taking care of her, she also farmed Robin out to baby-sit her sister Pam's children. It was like her mother was unable to function as the babysitting grandmother, so she used Robin as an extension of herself. She would constantly order Robin, "Go over to Pam's and help her with her kids." Soon Robin was acting as a second mother to her nieces and nephews. For years she spent every weekend there as their primary caretaker while Pam went to work. Even though her mother had originally coerced her into this role, she soon felt that caring for her nieces and nephews was now the main purpose in her life.

Robin had difficulty with dating. She has had romantic relationships with only three men in her life and says that only one of those was serious. This was when she was about 23 and they dated for about a year. Her boyfriend seemed to accept that her mother was mentally ill, but he would always get upset when Robin would run right home any time her mother called and wanted her. He would ask her why Robin was the one who always had to go. She had an older sister who lived right nearby. Robin would just tell him that Pam had two kids of her own, so it was Robin's job to take care of her mother. She and her boyfriend eventually broke up, this issue being one of the major factors.

Robin then felt that dating caused too much heartache and grief. After two more brief relationships that didn’t work out, she eventually stopped seeking a relationship. She feels that her issues around trust would make it difficult for her to have a successful relationship now even at age forty. Asked if her inability to trust others was a direct consequence of her mother’s schizophrenia, she replied:

> Oh, big time, because I don’t trust! Why would I allow you into my life, where everyone in my life has let me down? So, I’m going to let you into my life as a major partner…just so I can say, ‘Honey, go pick up bread’ and you come back with no bread? That would piss me off. So, I would rather go and get my own bread and just not deal with the romance aspect of my life…

She feels this lack of trust in others is quite directly related to her relationship with her mother because her mother should have been there for her emotionally, but she was not. Only in the past few years, after getting therapy for her depression, does Robin feel that she might be open to a relationship now.

Robin is not interested in having her own children even though she likes them. She says that she puts all of herself into her work as a behavioral therapist with children who have autism and that to also have a child at home to care for would feel overwhelming to her. Early on, she wanted to be a mother but over time this desire has faded. Robin still worries that she herself might still develop schizophrenia. Her mother had only started showing clear signs of mental illness around age forty-three and Robin at the time of interview was only forty. Robin feels her mother’s schizophrenia was triggered by menopause and fears this may happen to her as well at that stage. So, she would rather not take the chance of having children and then inflicting her own mental illness upon them. Another factor is that she feels she has done enough caretaking in her life, first with her mother and then with her father. She wants to have time for herself now. She says she has already fulfilled the maternal part of herself by helping raise her nieces and nephews and through her work with children. She also imagines that if she had her own children she would spoil them as she has “completely spoiled” her two cats.

While living with her mother, Robin got no reprieve in her role as her mother’s caretaker until her mother’s physical health began to deteriorate in her sixties. Robin worried that she might have emphysema from all the cigarettes she smoked. Her mother had severe edema in her legs and could no longer climb stairs, or at times even get up from a chair. She began sleeping downstairs in a reclining armchair for several months. She wore only loose fitting housecoats, so it was hard for Robin to see the exact condition of her body, but every time Robin suggested to Annette that she go to the hospital, her mother would refuse. Finally, one day her mother fell out of her chair and couldn’t get up. Robin helped her up and told her, “The next time you fall out of the chair I’m taking you to the hospital whether you are kicking and screaming or not.” Her mother stubbornly strapped herself into her chair with her housecoat cord to prevent further falls. Robin sensed that her mother was near the end and phoned both of her sisters to get there quickly. Both of her sisters gave her a hard time, telling her that she was over-reacting. A few days later, Annette fell out of the chair again and Robin called the paramedics. The doctor said she was suffering from congestive heart failure. Her legs were like thickened tree trunks and would both need to be amputated. The doctor described that she must have been enduring incredible pain. However, within twelve hours of her arrival at the hospital her mother passed away from congestive heart failure.

Her mother’s death filled Robin with fear. She was 28-years-old and in many respects felt like she had not started her own life yet. She panicked thinking, “Now I’m supposed to get my own life going. Boom, find a guy. Boom, get married. Boom, have a kid. But it just wasn't happening." She wondered, "Why is my life not working? Maybe because I was so freaking depressed!? Could that be!?" She found that she was not up to the challenge of becoming herself. She says, "not only did I not know what I wanted to do with myself, I didn't even know what my favorite color was!" One of her first therapists had her do an exercise where she had to list all of her likes. She found this a very difficult task and was only able to list about five things.

After her mother died, Robin agreed to move back in with her father in Florida to help take care of him, but with the understanding that she would finish her bachelor's degree in Education. Robin's oldest sister in North Carolina tried strongly to dissuade her from moving as she wanted Robin's continued help in raising her family. But, Robin refused her entreaties and went to live with her father. She had felt burnt out with teaching and began thinking about changing careers, or at least changing levels within the Education field. She applied for a bachelor's degree program in Special Education in Florida and sought any job at the University in order to get free tuition. After applying, but failing to obtain a receptionist's position, she saw a job opening teaching children with autism and got the job. She soon found that the field of autism was her niche:

> …Once I realized that these kids are just typical kids just needing tweaks, they hooked me because they keep me motivated. They keep me thinking and every time I see a behavior, I think, "How can I change that behavior to what I want it to be?" So, it's a very controlled and systematic (approach) and I think that's what led me to it…I needed that very systematic, very controlled area of my life, that I can control these kids. I can control their tantrums. I can control somewhat their behavior in certain aspects and I think I thrive off that.

Robin feels that her personal development was so thwarted by her mother's treatment of her as an extension of herself, and not as a person in her own right, that she failed to develop many aspects of her own individual personality. When the interviewer asked her to describe herself now, she sounded somewhat puzzled, paused and then replied:

> That’s the hardest part, is thinking about myself. I haven’t thought of myself in about forty years.

When Robin had turned thirty-seven, she was finally ready to go on her delayed journey of self-discovery. She decided to leave her father’s home in Florida and move to an entirely new region. She chose the Pittsburgh area even though she didn’t know a soul there. When she announced this decision, her father told her he was proud of her. He seemed to be aware without saying it that she had given up her individual life to be a caretaker first to her mother, then to her sister’s family and then to him. After all these years of defining herself through taking care of others, he was proud that she was now able to pursue her own life. However, when Robin arrived in Pittsburgh her depression intensified. She describes how she began to suffer from agoraphobia and social anxiety:

> And what did I do when I moved to Pittsburgh? I ended up turning into my mother where I didn’t want to leave my house. That’s scary… when literally you’re just fearful of walking out the door when God only knows what will happen next…I was a very functional depressed person because I was able to go to work (as a behavioral therapist with autistic children in their homes) because I was able to lose myself (in my work). For three hours (per session), I put my whole self into this child, to get the best results out of this child that I could. The minute I walked out, I was in tears. But, it didn’t matter because for three hours I was in an okay space because I didn’t have to worry about myself. And I would cry for 45 minutes in between clients. Go into that (next) house for three hours…fine, I was very functional. And then…I’m like that’s it. It’s over. I cannot live tortured like this anymore. My life was supposed to change when I moved up here…nothing is working. It’s all my fault, everything goes back to mom, … and that’s when I saw that ad for the research study on depression and I’m like they’re either going to help or they’re not. And I called that day and she’s like when can you come in and I was like you’re either going to help me or I’m going to die. And she was like can you come tomorrow? (Robin laughs). So I went.

Even contemplating suicide, Robin still could not place her own needs ahead of others:

> I then became suicidal and I was planning to kill myself. But even then I had a time frame, because I wouldn't commit suicide before my Dad had a planned trip to Europe with (my sister) Jeanine and (my niece) and this was like his dream…and that was three months (away) and I didn't want to ruin his trip. But, I know that when he went away that that is what is going to happen, (that I was going to kill myself), but I told (my therapist) straight out, 'You have three months. If you don't help me, that's that (I'll kill myself).' So (the therapy) worked, thank God…and I didn't even need medication, it was all just talking.

Robin feels her individual therapy was indispensable to her and changed her life. Some of her statements reflect that she continues to idealize her therapist and she described what "we" (she and her therapist) want for her life, rather than what she wants for herself. This seems to show she was not completely ready to stand on her own as an individual. Also reflective of this, she describes how when she first arrived in Pittsburgh she fell into a caretaking pattern with her best friend and her husband that was similar to her role in her family:

> It became, what do you guys need, not what do I need? I was like, oh you need to clean your house? I'll do it for you… You need your toilet scrubbed? I spent a whole therapy session on how I shouldn't feel the need to scrub their toilet (laughs).

At the time of the interview, Robin finally felt that her decision to leave and to individuate from her family was a good one. Her therapy helped to relieve her initial depression and pattern of dependency on others and she is ready to move forward and live her own life.

In looking back, Robin believes that her mother's schizophrenia was triggered in her early to mid-40's by menopause. (She says she knows that her mother had a difficult menopause because she shared a bedroom with her). She has discussed this theory in adulthood with her father who was 80-years-old at the time of this interview. Her father told her a friend's wife had become psychotic while going through menopause and asked Robin if she thought that was what had happened to her mother. Robin agreed with this. She notes that her mother also resisted treatment and "not once did she ever consult a doctor who might have been able to prescribe something to help her." Therefore, Annette was never hospitalized for any medical or psychiatric reasons until the day she went to the hospital and passed away.

Robin's relationships with her sisters continued to be somewhat strained even after her mother died, due to their differing perceptions of their mother:

> Jeanine (my middle sister) says I grew up in a different family because I have different memories of her (my mother), which is understandable. We're only two years apart, but at the same time it affects us differently.

Robin also had lingering resentment toward both of her older sisters for leaving her in the sole role of caretaker for their mother:

> I know while I was going through some of the hardest times, Pam (the oldest), the one who has the three kids now, would call me up and say, "Is mom in an 'in mood' or an 'out mood'?" And depending on (my mom's) mood was whether she comes over with the kids or not. (Did I) get a little resentful? Oh yeah…I did say to Pam on mom's final weekend…I think when all of this is said and done, I'm going to have one less sibling—and I was really getting rid of Jeanine because at this point I was so resentful of her…(But), how could she know what was going on when I really never opened my mouth and talked to her (laughs)? Because now that I think back, I can see that (laughs). But I just figured (at the time), she's in this mental health field, she knows how mom is, she should know what my life was like (as mom's caretaker), you know, that's it. And for her to even question that mommy was sick--I think that's where it got me --was when she questioned that mom was sick, called mom up, and I got yelled at for calling (my sister) and telling her mom was sick. That was when I was over and done with her (my sister Jeanine)…

However, after Robin had been in therapy for a while, starting at age thirty-seven, her relationship Jeanine began to improve:

> After everything's been said and done and mom's passed and I've been able to get into therapy, Jeanine and my relationship has gotten closer. Pam is going out there a little bit—she's just whacking out there a little bit. (She's) like I don't care what you do (with her kids)…Just her parenting technique is bothering me. I went down there (to their home) in November and all of her three kids had lice. And I went through their hair and my sister yelled at me for treating them like babies. Well, if you don't go through their hair, they don't get rid of it… so those little things. So, it's just really just bridged (sic.) a gap with us…So we have a good relationship but it's not as close as it used to be… So, really Jeanine and I have a much better relationship than Pam and I do which is really funny (because we never got along as kids).

There is also a strained relationship between Robin's two sisters to the point that they don't speak to each other. So, Robin acts as the glue to the family by running interference between them:

> Pam and Jeanine really don't talk to each other…Pam is very resentful of Jeanine for everything that Jeanine has (in terms of material things). And Jeanine is pissed off at Pam, because Pam doesn't get off her rear-end and do anything for her family… so I'm the one who plays the middleman. So like Jeanine wanted to have a surprise party for Daddy, so Jeanine called me to call Pam to see if she can come…She will never call her directly, never.

Robin now at age 40 is finally comfortable with herself and her role in the family. The geographical distance she has put between herself and them has allowed her to step out of her caretaking role and just be a member of the family. She is able to enjoy her job and spending time with her best friend.

When asked to identify her sources of resilience on a scale of 1-5, she gave surprisingly low marks for almost everything. Her father, her sisters and her friends all received scores of 2. Her mother, grandparents, other relatives, teachers, coaches, mentors all got zeros. Her "belief in God or a higher power" got a 2. However, "doing things for others” and her “own drive to succeed” received high scores of 5. Like several of the other interviewees in this study, her own desire to succeed on her own and her doing things for others is what has been healing to her. Despite her not being emotionally nourished by her mother, she has finally learned to do this for herself.

Asked what she would say to her mother now about her childhood experience coping with her mother’s mental illness, Robin responded:

> She let me down. I wish I had a real mom. I wish I had a mom who wanted to do the girlie things, to participate in my life’s journey. That’s all I really wanted was somebody that was a confidante, who wanted to participate. So, she was a major disappointment in my childhood.

Advice that Robin would give to a child today living with a mother who has schizophrenia is:

> Believe in yourself, believe in yourself, believe in yourself. You are a great person. You don’t need anybody to tell you that you’re great. Know it for yourself, which is the hardest thing to do when you’re a kid.

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