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Jones, Samuel Carl, D.S.W.

City University of New York, 1992

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SCHIZOPHRENIA AND THE FAMILY LIFE CYCLE

by

SAMUEL C. JONES, C.S.W.

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Social Welfare, The City University of New York.

1992

This manuscript has been read anad accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

12/18/91
Date

Irwin Epstein
Chair of Examining Committee

12/18/91
Date

Executive Officer

Irwin Epstein
Mildred D. Mailick Mildred Mailick
Meryl Singer, CSW
Meryl Singer, C.S.W.
Supervisory Committee

THE CITY UNIVERSITY OF NEW YORK

Abstract

SCHIZOPHRENIA AND THE FAMILY LIFE CYCLE

by

SAMUEL C. JONES, C.S.W.

Advisor: Professor Irwin Epstein

This study, which is based on Wynn's (1988) epigenetic model of family process and Carter & McGoldricks (1980) model of the family life cycle stages and tasks, looks at how families negotiate life cycle tasks when one of the children suffers from schizophrenia.

A stratified random sample of urban, multi-racial, English speaking parents (N=30) with schizophrenic children were interviewed. They all fell within the last three stages of C & M life cycle model which is when schizophrenia tend to be present.

The respondents were asked question developed from the C & M family life cycle model, Rolland's (1987) chronic illness and life cycle framework and Combrink-Graham's (1985) developmental model for family systems. The F-COPES instrument was also used to assess problem solving attitudes and behaviors which families develop to respond to difficulties.

The results indicated that the success of a family in negotiating life cycle tasks is dependent on a variety of variables within the family. The process of negotiating tasks is not all together stopped. It is often frustrated and slowed down depending on family internal and external resources.

ACKNOWLEDGMENTS

The epigenetic principle which is a major part of the theoretical base of this study holds that the successful negotiation of life stages is directly dependant on the successful negotiation of preceding events. That theory is supported by the process and variables which led to the completion of this dissertation. Every stage of this process was based on the foundation which was laid down by the previous accomplishments. Each accomplishment was achieved because of the support of important individuals who valued my effort as much as I did.

I would like to recognize the people who in their special ways contributed to my successful negotiation of this life event and milestone.

First I will like to thank the families who consented to share their private thoughts and experiences with me.

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Schizophrenia has afflicted mankind for thousands of years. It is a condition so severe and debilitating that many mental health professionals consider it to be the most serious of all mental illness. The psychological, medical, and sociological literature is replete with theories and reports about the role of the family in the development and maintenance of the illness. Often the family itself has been characterized as toxic in causing or exacerbating the condition.

On the other hand, the literature regarding the effect of the schizophrenic on the family and the family's attempt to negotiate life cycle and developmental tasks is sparse, if not completely ignored. As a result, one must go to the literature on the general impact of mental illness on families for any sense of the family's burden--emotional, financial, social--when living with mental illness,

In spite of these stresses, the 1960's policy of deinstitutionalization released in excess of one million mental patients to the care of their families. Follow up on this patient population by a number of researchers such as Lamb(1982) and Woesner(1983) indicated that implementation of this policy wrought havoc among families in terms of added burden and stress.

Understandably, the issue of burden has now become a focus of inquiry among researchers. The "burden literature" has shown that such families often experience an increase in financial responsibilities, a disturbance in domestic routine, profound interference in their social and professional lives, and a reduction in the amount of attention other members of the family are able to receive from the family and from parents in particular, (Mandelbrote & Falkard, 1961; Grad & Saindury, 1963; Hoening & Hamilton, 1966; Herz, Endicott, & Spitzer, 1976; Hatfield, 1978; Thompson & Doll, 1982)

Schizophrenia appears to be an illness which has a powerful impact on family systems and life cycle processes. Even under the best of circumstances, the life cycle by definition requires adjustment over time. Moreover, according to Gubman and Tessler's review of studies on the effect of mental illness on the family "...provides ample evidence that the presence of mentally disabled members creates difficulties and requires that the family make a number of adjustments. It is not clear how the adjustments affect the weight of the family's burden in general.

Family therapists have begun to recognize the need to focus on the family's developmental and life cycle issues relative to their ability to manage schizophrenic family member and to respond to the vicissitudes of the life cycle at the same time. However, our knowledge of schizophrenia and its relation to adult and family development is still primitive and inadequate.

For over two decades there has been vigorous debate about the psycho-genesis and treatment of schizophrenia within the field of family therapy and about the value of family therapy in treating schizophrenics (Jackson, 1957; Wynn, 1958; Lidz, 1949; Bowen, 1960).

One side in this struggle has allied itself with psychodynamic and systems oriented thinkers (Ackerman, Bowen, Fromreichman, Bateson, Hailey, Manuchin, etc.). The other side, the bio-social school, led by Anderson, Hogerty, Falloon, McFarlane, Bernheim etc., has attacked psychoanalytically based concepts and treatment methods. They are armed with new biological information about the human brain, communication, stress management and their relationship to schizophrenia. Information about the brain and stress management are largely contributed through new technologies such as Computerized Axial Tomography (CAT), Nuclear Magnetic Response scanner (NMR), Regional Cerebral Blood flow scanner (RCBf) and the Positron-Emission Tomography scanner (PET scan).

Despite their differences, both sides agree that schizophrenia is a family matter. Both sides agree that the family has enormous influence on the course of the illness, and both sides tend to focus therapeutic efforts on the family's interaction with the afflicted member.

Most of the obvious similarities between the two groups ends there. The psychodynamic side is firmly rooted in the assumption that schizophrenia is largely an illness of the mind. They believe the problems of the mind result from pathological intrapsychic, interpersonal and systemic transactions. They also believe that the seeds of these significant transactions were sown during the first five years of life. As a result, family therapists have historically placed particular emphasis on two significant constellations; the mother/child relationship and the parent dyad.

The bio-social school takes the position that schizophrenia is first and foremost a physical illness with psychological and social ramifications that is largely rooted in the biology of the human brain. They believe that the brain, for a variety of reasons, is faulty in processing information and in regulating both internal and external stimulation. They also believe that the behaviors and dynamics of the families observed by the psychodynamic school of thought are not uniquely attributable to schizophrenia. Instead it is largely a consequences of a family having to deal with the stress of illness that is not well understood. They reject the notion that the pathological behaviors and structures observed in these families causes schizophrenia. Instead they place emphasis on affecting the variables that are likely to influence the course of the already afflicted person and persons rather than those variables that may have caused the illness.

Both schools of thought have continued to refine and solidifying their theories and treatment techniques for schizophrenia and the role families play in the treatment of the illness. In the parallel evolution of each school of thought, it is becoming clear that they are not inherently incompatible. In fact there is an increasing likelihood that these two perspectives may represent two sides of the same coin.

Regardless of which school of thought one embraces in the treatment of families with a schizophrenic member, the therapist inevitably encounters a number of treatment issues that are solidly imbedded in the developmental course and/or life cycle of the family. These issues can impede or, if properly addressed, may sometimes facilitate the therapeutic process. More often than not, they seem to interfere with the therapists attempt to bring about desired or indicated changes in the family.

These developmental and life cycle issues include the shifting of physical, economic, intellectual, and social power from parents to child as each gets older. The focusing and re-focusing of life goals and responsibilities as well as life expectations; the realignment of relationships; the dealing with losses of significant individuals through the natural aging process and the review and reconciliation of these losses; and the preparation for death of parents are all important issues to be addressed. These are normal developmental and life cycle issues for all families (Carter & McGoldrick 1980).

Examples of these stresses when schizophrenia is present include, the disrupted plans and hopes a parent might have had for a once promising child, or the financial burden of having to support a chronically ill child well into adulthood. Also important is the additional social isolation, stigma, and burden the illness may causes aging parents as they enter a phase of life in which their resources, social supports and social network tend to shrink (Kahn and Antonucci 1980, Shanas 1979, Pilisuk & Parks, 1986). These parents are placed in the position of trying to manage a younger more powerful, possibly threatening and often delusional person.

There are also concerns of mortality on both the patient's and the parent's part. Frequent questions and concerns of parents are, who will take care of my child when I am no longer able to do so. Patients, on the other hand, may also be concerned with who will take care of them when their parent or parents dies.

Although all families in this culture are faced with these life cycle and developmental issues in one form or the other, the question of what specific resources are needed in this process are important issues. How the family with a schizophrenic member adapts and maintain cohesion while dealing with these and other related issues is the central question that this project hopes to answer.

Unfortunately as Celia Falicove (1988) so clearly points out, we know more about the life cycle of the ordinary fruit fly than we know about the development of the adult individual and even less so about the family. Comparatively speaking, we know very little about what internal stresses facilitate the changes in normal family transitions.

We know little about the effect of chronic illness on the ability of a family to negotiate transactions and life cycle issues. We know even less about the effect schizophrenia with its special features, has on the family's ability to successfully[1] move from one life cycle phase to the other.

The information sought in this study will assist in answering questions such as: do these families successfully negotiate the

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[1]. Success in this context is achieved when the family is no longer hampered by the tasks of one life cycle stage and is in the process of resolving or successfully negotiating the tasks of the subsequent stages.'

normal development and life cycle issues? If they do, <u>how</u> do they do it and what resources are needed? What happens when successful adjustment does not occur? How do they feel about their situation? What about the presence of schizophrenia prevents the successful negotiation or adjustments from happening? What can be done to help the process.

Since Erik Erikson's <u>Childhood And Society</u> (1950) there has been a growing awareness and academic interest in the human life cycle. Levinson (1978) added to the interest with his ten-year study of adult development. His description of the evolution of 40 adult males over a 10-year period, suggested that adults continue to develop throughout their lives and are not necessarily doomed to follow the psychological path laid during the first 6 years of their lives. Gail Sheehy, borrowing from Levinson's work popularized the topic in her book <u>Passages</u> (1976).

In the field of family sociology, Hill and Duvall (1948) took a first steps toward the outlining and understanding of what we now call the family life cycle. Their work took an eclectic, integrative approach that included the concepts and knowledge of child development, sociology of work and rural areas.

Hill and Duvall's work supports the notion that individuals and families continue to change and grow throughout their lives. For the family, changes tend to be in form and function. Within the family unit, the individual changes his form and function over time as well. Developmental theories suggest that both individual or family level changes occur in an ordered sequence of developmental stages.

Lyman Wynne(1988) has contributed to this notion of ordered, and sequential change through the development of the *Epigenetic Theory of Family Process.* Wynne stated that the Epigenetic model of family process" builds upon the core hypothesis that relational processes within families and other enduring interpersonal systems follow one another in a certain developmental sequence"(Wynne, 1988).

In subsequent revisions of his theory, Wynne (1988) points to the transitional periods and underscores their importance to the epigenetic developmental process. Wynne points out that the most critical criterion for making transitions and building on the previous stages in the developmental process, is the entry and exit of individuals within the family. The entry and exit of individuals changes the form, structure, composition and function of the family.

Wynne expresses concern for the family system when the quality of the familial relationships is inappropriate or when it provides a poor fit between the individuals and the structural change of the family. For example, what occurs when the parental dyad is no longer able to provide intensive parenting in the form of structuring, support, discipline, instrumental resources, nurturing etc.. On the other extreme, what happens when a young child is required to act as a parent on a full time basis. If the disciplinarian parent has departed from the family and the remaining parent is unable to perform that task, what are the options available to that parent.

The presence of schizophrenia in a family causes enormous stress for the entire family unit and for the parents in particular (Hatfield 1979). Despite the burden and stigma of having schizophrenia in the family, many families seem to achieve the normal developmental tasks of the life cycle. This study also seeks to determine what allows some to successfully manage these developmental tasks while others fail.

In attempting to answer the questions this topic raises for clinicians and for researchers alike, this project will focus on three stages of the life cycle. The specific stages are what Carter and McGoldrick's (1980) refer to as stage #4 The Family With Adolescents, Stage #5 Launching Children And Moving On, Stage #6 The Family in Later Life.

These three stages are the stages in which schizophrenia most frequently tends to appear in the family's life cycle. According to the Diagnostic and Statistical Manual III-Revised, the onset of schizophrenia usually takes place during late adolescence (age 18) for men, and early adulthood for females. The age of vulnerability then extends into the mid-twenties for men and the later twenties for women. The illness is a chronic one with a gradual deterioration in the afflicted person's ability to function independently. There is currently no cure at this point. illness.

However, recent longitudinal studies have challenged this previously held pessimistic view of the illness (Harding 1987). The illness may not necessarily be degenerative or permanent in a very damaging way for everyone. Hence the illness is not necessarily chronically degenerative and completely debilitating if its course is somehow made less severe (McFarlane 1984, Harding 1987, McFarlane unpublished 1989). The less severe the course, the less debilitating the illness. This seems to be the case, even though vulnerability to the exacerbation of symptoms is chronic.

The family's influence on the course of the illness is well documented (Brown, Carstairs, & Toppin, 1958) (Brown, Monck, Carstairs,& Wing, 1962) (Lidz 1965) (Hoenig 1974) Tarrier, Vaughn, Lader,& Leff, 1979; Sturgeon, Kuipers, Berkowitz, Turpin, & Leff, 1981). Since the deinstitutionalization movement of the late fifties' and sixties', it is estimated that as many as 90% of all mental patients have regular contact with their family members. As many as 60% live with their families. Since Schizophrenia is the most commonly occurring mental illnesses, it is estimated that over half of all mental patients in this country are afflicted with schizophrenia.

It is relatively easy to estimate how many schizophrenics have regular contact or live with their families (Falloon, 1984) and the effect those contacts have on the patient. Little has been done however to explore the effect the illness has on the family's developmental and life cycle issues or the development of the individuals within the family. This exploratory study will attempt to describe this phenomenon and present data that may contribute to theory building in this area.

SECTION ONE

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

CHAPTER I

FAMILY DEVELOPMENTAL/LIFE CYCLE/STRESS THEORIES

INTRODUCTION

Family developmental, life cycle and stress theories will be presented as they pertain to schizophrenia. This chapter will explores the sociological roots of family life cycle and development and its merger with fledgling systems thinking family therapists who were attempting to find apropriate responses to post World War II

psychiatric and psychological problems.

FAMILY DEVELOPMENT/LIFE CYCLE THEORY:

The family life cycle as a clearly identified and conceptual framework is basic to the field of family therapy. Considering its importance and its widespread application in clinical practice, especially among family therapists, one could easily believe it is the work of family therapists and the family therapy movement. However, that is not the case; It was not until the early 1970's that the concept was crystallized and the phrase "family life cycle" appeared in family therapy literature.

The concept originated in sociology. As previously stated, Rubin Hill and Evelyn Duvall are recognized as the first to research this stages of family development. Their observations were reported as a background paper for the National Conference on Family Life in May, 1948. They observed that each member of each generation in a family seem to have separate developmental tasks to perform. They also observed that the success of a member of one generation in achieving or successfully negotiating their developmental tasks, impacts positively on the other members in achieving their developmental goals (Carter & McGoldrick 1980).

At this point it is important to recognize that the family life cycle is not synonymous with family development. The family life cycle as a structural concept is both the byproduct of the sociological family development theory on the one hand and psychodynamic and systems theorizing about the family on the other.

According to Duvall (Falicov 1988), the family life cycle reflects "those nodal events that are tied to the coming and going of family members, such as the birth and raising of children, the departure of children from the household, retirement, and death". (Duvall 1957). At that point in its theoretical evolution it was primarily a microconcept that focussed on and revolved around the biological changes of family members.

The family life cycle concept is part of, or is included in the larger more encompassing family developmental framework. As such it focuses on specific structural organizational and adaptation changes in family composition.

On the other hand, Falicov defined family development as "an over arching concept, referring to all transactions and co-evolutionary processes connected with the growth of a family. These include processes of continuity and change connected with work or occupational development, relocation, migration and acculturation, acute or chronic illness, or any set of events that significantly alters the texture of family life". This is a macroconcept more closely associated with external as well as structural changes.

FAMILY DEVELOPMENTAL FRAMEWORK:

The family in post WWII America faced a number of demographic, economic, psychological and sociological problems. Most families adapted to these changes and continued to flourish. However, many began to exhibit unfamiliar problems, most of which were caused by the loss of significant family members during the war. These losses were either of a temporary or permanent nature. Some of those who returned from the war, returned physically damaged and could not resume their expected roles or functions within the family. Others had difficulty adjusting to the structural and psychological changes that has occurred within the family unit during their absence.

These events precipitate a need to understand what was going on in these families and families in general. There were many questions regarding the definition of the normal family; how do families change and adjust to change; how significant are the roles of individual within the family; what can be expected of individuals within the family unit; and how can families be helped to adjust and re-stabilize after major changes have occurred. New theories and perspectives were needed to answer many of these questions.

The developmentalists believed family changes took place in an ordered sequence of stages. Hill considered three types of changes; family size, age composition, and work status. New developmental stages defined new and appropriate roles because of aging, or the addition, or loss of family members. The framework also postulated that the developmental stages that are discrete and discontinuous require major reorganization of family roles as they occur (Hill & Mattessich).

This theoretical perspective was not particularly attractive to the budding family therapy movement and therapists who were attempting to treat family problems. In part this was because it lacked a psychological explanation and specificity about what impact these changes had on the emotional functioning of the individuals within the family and/or the family as a unit. The developmentalists contribution was at a purely descriptive level. They did not focus on the content and emotional significance of these changes. They did not recognize nor express interest in the stresses that experienced clinicians knew families endure as they attempt to negotiate developmental changes.

The families who sought help from therapists were often stressed and dysfunctional because of the difficulties associated with these changes, or when changes did not occur as expected. This was understandable since the original family developmental concept was not intended for clinical use. It became one of the most revolutionary concepts in the field of psychotherapy since drive theory was replaced by ego psychology and object relation concepts and structures.

The concept of the life cycle is now basic to just about every psychotherapeutic intervention made by clinicians working with individuals or families.

STRESS THEORY:

The emergence of new family constellations, demographic, sociological, psychological and economic changes of post WWII America, created a sociological and therapeutic need that required a bridge between the sociological research and theorizing and family therapy practice.

In 1949, Hill introduced stress theory, another major development in the area of family life cycle and development theory and research. Hill's Stress theory was represented by the ABC-X model. In the model, A, represents the stressors, B, represents the family's resources, C, is the family's interpretation of the events, and X represents the outcome. This model and the accompanying theory proposes that expected events and life cycle changes can be as stressful and require as many resources to negotiate and adjust to as unexpected events.

Stress theory became the bridge between the non-clinical sociological family developmental theory and the family therapy perspective and experiences about family functioning. An attempt to include both observational and content issues were addressed by this theory.

The notion of pile-up of stressors (Hill, 1949), incorporated the concept of coping and adaptation in which family symptoms were viewed as problems of adaptation. The notion also made the models more attractive and relevant to clinicians. Later, the model as a possible tool for family clinicians, received more acceptance when Rappaport (1963) introduced the concept of family developmental crisis and periods of transition.

There has since been a shift toward examining the family's response to an accumulation of demands over time (Hansen & Johnson, 1979; Hill, 1973; Mechanic, 1974). According to McCubbin and Patterson (1973), these demands are comprised of two types, stress, and strain. Stressors are discrete, objective life events or transitions that may produce change in the family structure, form, resources etc.. Strain, on the other hand, is a more subjective feeling is an emotional response to a situation and the desire to change things for the better.

It is generally accepted that the accumulation of stressors have a deleterious effect on a family's adaptability and sense of well-being (Hansen & Johnson, 1979; Hill, 1973; Mechanic, 1974; McCubbin & Patterson 1982,1983; Lavee & McCubbin, 1985). A family experiencing a high level of stress and strain could not function at its optimal level.

This embryonic phase in the evolution of the family life and development cycle theory became well-established in the academic community. Recognizing the changes families endure when stressed was critically important. The concept was now ready to move on to the next level of its own development.

THE FAMILY LIFE CYCLE:

Family research and theory building reached another level of maturity in 1950. During a workshop on marriage and family research, Duvall (1957) unveiled her work which led to the division of the family life cycle into eight stages. Seven years later she published the first edition of her outline of the developmental task of each stage. This work is still considered the basic text in the field of family development.

Following these landmark contributions, sociological family developmental framework went through further refinement and articulation. A number of studies were conducted which focused on the normative patterns of marital satisfaction over the life cycle. These were influenced by the developmental perspective, (Blood & Wolf, 1960; Klein, Jorgensen, & Miller cited in Hill & Mattessich; 1979; Menaghan, 1983; Rollins & Cannon, 1974; Rollins & Feldman, 1970; Spanier, Lewis,& Cole, 1975).

Recognizing the significance of the family developmental framework to the emerging family therapy movement, family sociologist once again sought ways of integrating family therapy's theoretical perspectives into the family developmental framework concept.

In 1971 Hill focused on general systems theory and summarized four groups of concepts relevant to the family life cycle aspects of the developmental framework (see previous definition of Family Life Cycle and Family Development). The four groups were: (1) the family as a relatively closed social system which maintains boundaries and seeks equilibrium; (2) concepts of structure, such as positions, role norms, role clusters, and complexes; (3) concepts of goal orientation and direction; and (4) concepts dealing with sequential regularities such as stages of development (Falicov, 1988).

Hill believed the first group of concepts, "the family as a social system", provided the greatest overlay between family systems theory and the family development framework. His conclusion is based on two areas of similarities, the "Interdependence of parts" and "degree of openness and permeability of boundaries".

More generally, these concepts are summarized and operationalized in a number of models of family health and measures of family functioning. The most prominent models and probably the widest used in the family therapy and family developmental field are the Beavers-Timberlawn Model of Family Competence and the Circumplex Model of Adaptability and Cohesion by Olson, McCubbin et al.(Green, Kolevzon, Volser, 1985)

The Beaver-Timberlawn model suggests that family functioning is on a continuum which goes from the less functional to the more functional in terms of structure (power structure, parental coalition, and closeness in the family), mythology (how families view themselves), goal-directed negotiation, the autonomy of its, members, and the nature of family affect and its expression. Thus, the higher a scores in this area, the more functional the family.

The Circumplex Model stresses the balance between two primary variables--cohesion, adaptability. Olsen et. al. (1983), defines adaptability as "the marital/family's system ability to change its power structure, role relationships, and relationship rules in response to situational and developmental stresses". Cohesion is defined as "the emotional bonding that family members have toward one another". The dimensions of cohesion are; emotional bonding, boundaries, coalition, time, space, friends, decision-making, and interests and recreation.

Optimal family functioning is achieved when a balance between the degrees of these two variables reach a midpoint between dysfunctional extremes of both adaptability and cohesion. The range for adaptability are chaotic, flexible, structured and rigid. For cohesion the range includes disengagement, separation, connectedness and enmeshment.

When one variable is placed on the Y axis and the other on the X axis, a matrix is formed with 16 discrete combinations of family types. Thus the combination of flexible, separated flexible connected, structurally separated, and structurally connected, are the four mid-ranges of optimal functioning.

These models have significant methodological and measurement differences. Proponents of each challenge the validity of the other while advocating the validity and strengths of their own. Notwithstanding these theoretical advocates and detractors, it has been argued as well that both models are measuring basically the same phenomenon and both are valid and reliable (Green, Kolevzon, Volser 1985).

This project will take the position that schizophrenia can cause variations in a family's ability to maintain cohesion, develop clear modes of communication or exercise appropriate adaptability skills that can significantly influence the successful negotiation of developmental and life cycle tasks. The stresses of living with schizophrenia are believed to influence the family's adaptability and cohesion to a range beyond normal. Thus the focus on the adaptation, strengths and methods used by families in negotiating life cycle stages and the issues involved in dealing with the presence of a schizophrenic member, become directly relevant to this study.

Another central concept in the theoretical focus of the project is the "interdependence of parts". This means that the effect of the whole unit is sometimes greater and sometimes less that the sum of its parts and "degrees of openness and permeability of boundaries" highlight the issues of equilibrium. It also maintains family boundaries in order to maintain group integrity while allowing for growth and the emancipation and inclusion of valued individuals and members.

There are times in the life cycle when great flexibility is needed and times when it is counter-productive, and both are important in the treatment and management of schizophrenia. Olson et. al. (1983) defines adaptability as "the marital/family's system ability to change its power structure, role relationship, and relationship rules in response to situational and developmental stress". And cohesion is defined as " the emotional bonding that family members have toward one another". The dimensions of cohesion are; emotional bonding, boundaries, coalitions, time, space, friends, decision making, and interests and recreation.

The problem of schizophrenia is more than an individual's ability to function on an optimal level. It is a profound challenge for that persons family as well.

THE LIFE CYCLE IN FAMILY THERAPY:

Although trained as a psychoanalyst, Pollack (1956) chose a sociological concept to explain his belief that the pathology in an individual is not entirely his own but should and can be shared by the his family. The idea that the family is a small social group that undergoes developmental changes much like any other social group was basic to his view. Difficulty making these changes resulted in the symptoms that therapists attempt to treat. Pollack theorized that the attention to need, and complementarity at various stages of the family's group development was essential for successful transition and eventual growth of the group as well as the individuals within it. He hypothesized that families experience various stages, and that those stages require different resources from individuals as well from as the unit as a whole.

While appreciating sociological concepts, psychoanalytical thinking continued to strongly influence the development of Pollacks's theories. This is exemplified by the presence of the concepts of regression and of psychological developmental needs in his formulation.

This type of eclectic thinking also reflected the embryonic stage of development for the family therapy field. During the mid-1950's Nathan Ackerman was in the forefront of the field, and most of the work done at that time was still heavily influenced by psychoanalytic concepts. Ackerman attempted to apply basic beliefs about the intrapsychic dynamics of the individual to the family unit.

In 1971 SOCIAL CASEWORK posthumously published the work of F.H. Scherz which appears to have been the first description in family therapy terms of how individuals and family developmental tasks interrelate and influence each other. Scherz believed that universal family tasks were interwoven with individual developmental tasks. The successful negotiation of these tasks require a shift in object relations, identifications and marital equilibrium.

Like many other family therapists as well as family sociologists who were interested in the bridge between family sociology and family therapy theory, she believed the developmental and life cycle changes brought with them stress, tensions, conflict and the potential for emergence of family and individual pathology. Her stages and tasks reflected the influence off Erikson's and lidz's. Her transitional, developmental, and maturational crisis stages were: intimacy vs. distance, acceptance vs. competition, enabling vs. undermining, exposure vs. encapsulation, consolidation vs. confusion, and release vs. adhesion (O'Connell 1972).

One can also see the influence of other cybernetics and systems theory concepts such as centripetal and centrifugal forces in family function in Scherz's formulation. Much like Pollack, Scherz was heavily influenced by the predominant psychoanalytic concepts. As the field of family therapy grew, a variety of conceptual models developed. The concept of the family having a life cycle was either tacitly or directly and consciously included in many theoretical constructs.

Falicove (1988) has pointed out that aspects of the developmental and family life cycle concept can be found in all the major models of family therapy. However, there are some models which utilize more developmental and life cycle concepts than others. Jay Haley and Michael Solomon, both of whom were influenced by Erikson, are credited as the first to include the concept of the family life cycle in the family therapy literature. (Their respective publications appeared in 1973), Solomon's article which appeared in the well known family therapy journal Family Process, outlined the life cycle in which the mastery of each stage is necessary for the ascendancy to the next level. Solomon's life cycle stages begin with marriage, then the birth of the first child and subsequent children, the individuation of family members, the departure of children, and the integration of loss.

Building on the work of Erik Erikson, Jay Haley in Uncommon Therapy(1973), described the family life cycle in six stages. They are: courtship, marriage and its consequences, childbirth and dealing with the youth, middle-marriage difficulties, weaning parents from children, and retirement and old age.

Haley believed that some families become mired at transitional points, producing symptoms in need of treatment. He believed transitions are the most difficult and stressful aspects of the life cycle because families are required to make changes they may not be prepared for or willing to make.

Both of these authors deserve the credit they have received for the formal introduction of the concept of the family life cycle to the field of family therapy. However, credit should also be given to a few other pioneers who saw the importance of the family life cycle to the understanding of family functioning as well as to the development of therapeutic interventions for treating families locked into these transitional periods.

Falicove (1988) has painstakingly reviewed all of the major theoretical models of family therapy in terms of their basic concepts and utilization of life cycle ideas, family dysfunction, theories of change and therapeutic goals. She concludes that "The structural school takes normative expectations into account when delineating goals for families, whereas the Milan systems approach purposely avoids imparting a normative direction to the therapeutic goals.

In comparison, the psychodynamic/intergenerational and symbolic-experiential approaches use the life cycle framework as well as other current aspects of family development (career line, phase of illness) as background or contextual information only. More emphasis was placed on a multi-generational historical understanding of family development, using other explanatory concepts, such as triangulation, projection, or unresolved grief. Falicove goes on to say, "The structural and strategic models emphasize present family stresses and attempt to label problems as transitional whenever possible".

The psychodynamic/intergenerational theories postulate that unresolved past issues are involved in the present problems. Thus they interpreted the problems as deeper than transitional stress. Although some psychoanalytic family therapists (Barnhill & Longo,1978; Skynner, 1981) integrated the life cycle concept and framework, they also ultimately considered life cycle stresses per se as "insufficient to bring about symptomatology unless they uncovered a larger problem of past family development" (Falicov 1988).

Recently two models of family development and the life cycle have surfaced which seem to have the potential for wide application at this point. They are the Carter & McGoldrick (1980) model, and the model of Lee Combrinck-Graham (1985).

Though each school of thought has its strengths with particular families and at particular stages, the Carter & McGoldrick model seem to have the widest yet most specific application with particular problems. In its six stages of development beginning with *The unattached young person* to *The family in later life,* the model seems to address both the structural, transitional issues as well as the epigenetic intergenerational issues. It focuses on family roles, hierarchies, linkages, and emotional and functional transitions.

Carter and McGoldrick's model and most developmental models have been criticized as not being a model of family development, but an individual approach to development adapted to a systems family model. It has been pointed out that since most models use children as a marker, they may lack diagnostic accuracy where there are no children in the constellation.

Carter and McGoldrick are criticized by Combrinck-Graham (1985) for having some of these shortcomings. However, she also recognizes their major contribution to the thinking of developmental stages as involving reciprocity within the family system.

She proposes that the family life cycle is not simply a series of stages that build on and follow each other, as the epigenetic theory proposes (Wynne 1984, 1988). Though family life cycle does not have a beginning or an end, the individual's development and life cycle do have a beginning and an end. However, in our society most families do not end. Instead death is something that occurs within the context of the family life cycle, and in the case of this project, the appearance of a chronic illness is another factor or event in the life cycle of the family and the individuals within it.

To emphasize her contribution to the evolution of the family life cycle concept, Combrinck-Graham felt it necessary to change the phrase "life cycle" to "life change events". She sees the life cycle/life change as a spiral in which there is a reciprocal relationship between generations in the development and negotiation of their developmental task.

In Combrinck-Graham's model, the developmental tasks of one generation are superimposed. She cites Erikson's developmental stage of generativity as an example where young adults are most appropriate for giving birth to and rearing young children. The presence of young children may then affect the generativity of young parents.

The next step in this model was to categorize and label these reciprocal phenomenon throughout the life cycle. The concepts of centrifugal and centripetal systems were proposed. Instead of having 6 developmental stages as in the case of Carter & McGoldrick, Combrinck-Graham saw a repetition of these two forces at various times in the life cycle. The family in the centripetal system is characterized by enmeshment, the diffusion of interpersonal boundaries and a high degree of resonance among individuals within the system. The activities that represent these dynamics are the formation of long term relationships, the nurturing and solidifying of that relationship to the exclusion of others, and the bearing of a child or children.

A family in a centrifugal process is coming apart. The process may be influenced by the rate of success of tasks in the preceding centripetal phase. Here there is a resemblance to the epigenetic theory: but it is not linear. Theoretically the younger generation may be entering adolescence, the middle generation (parents) may be entering what is known as the mid-life crisis, and the older generation (grandparents) may be entering retirement. Every member is dealing with issues of role, personal identity and personal goals, either in terms of setting them or reviewing them.

Once again the issues of stress, strain, adaptability, cohesion and communication are seen in the concepts of centrifugal and centripetal systems.

SUMMARY

The background from which the ideas of this investigation were conceived, and the theoretical base upon which it was built was presented. The sociological beginnings of the family life cycle concept was outlined as well as the psychological community's eventual embrace of Hull and DuVall's contribution to better understanding aspects of the human condition.

The stages of Carter & McGoldrich's Family Life Cycle outline as widely employed by family therapists was also presented as well as an explanation of its central role in this study. There was further review of the sociological concepts of the developmental stages contributed to the development of other aspects of family therapy.

SCHIZOPHRENIA

INTRODUCTION

The phenomenon of schizophrenia as it pertains to this study is presented. A brief history of the illness will be followed by an outline of the major theories of its etiology. The theories presented will be the major theoretical structures from which the phenomenon is viewed. Some of these theories such as those which place the cause of schizophrenia on the family, will be examined in terms of epidemiological data. Finally knowledge about the relationship between the family and schizophrenia will be discussed.

HISTORY OF SCHIZOPHRENIA:

The Diagnostic and Statistical Manual 3rd Edition Revised, defines schizophrenia as "...the presence of certain psychotic features during the active phase of the illness, characteristic symptoms involving multiple psychological processes, deterioration from a previous level of functioning, onset before age 45, and a duration of at least six months. The disturbance is not due to an Affective Disorder or Organic Mental Disorder. At some phase of the illness schizophrenia always involves delusions, hallucinations, or certain disturbances in the form of thought disorder".

Schizophrenia is not new to the human experience. Descriptions of conditions that are believed to be schizophrenia have been found in a Hindu fragment from the Ayur-Veda writings from India as far back as 1400 BC (Freedman, Kaplan, Sadock 1976). McFarlane speaks of numerous descriptions in the Bible of behavior that can be classified as schizophrenic in nature (McFarlane 1984). A number of individuals referred to in the Bible have experiences in which they heard voices, had visions, spoke in strange tongues, and experienced lability of mood and affect. Even though some or most of these may have been divine experiences, one may assume that many were of a symptomatic nature. There are numerous references to schizophrenia or other psychotic process as in the literature of Western civilization.

Advances in the natural sciences occurring during the latter part of the nineteenth century and the early part of the twentieth century introduced neurology as a major medical discipline. The mapping of the nervous system just about completed and advanced the understanding of the brain (Anderson 1984). It was believed in the scientific community that the brain and all its functions would one day be completely understood.

Freud participated in that enthusiasm and was very much in tune with the mechanistic and empirical philosophy of science at the time. As a researcher and one who was originally interested in studying the brain (and not the mind), Freud hoped to find ways of mapping its functions. In this regard he was directly influenced by Brucke, Meynert, Charcot, and other prominent physicians who studied the brain.

Broca and Wernick proved that specific areas in the brain controlled specific functioning and that damage to these areas resulted in particular functional deficits for[2], Golgi and Nissl developed new and exciting methods of staining slides and specimens which allowed brain cells to be observed more closely under the microscope[3]. Freud, still a young and aspiring scientist, hoped for an academic appointment at one of the major universities in Vienna where he could pursue his dream of participating in this revolution.

This hope was thwarted by growing anti-Semitism in Germany, and as a result he turned to private practice to support his family. Ironically, the result of this "lock out" was far more significant and influential to the Western world's thinking than the bigoted academics who excluded him from the "Biological Revolution" could have imagined.

To earn a living, he began to treat the hysteric symptoms of wealthy Viennese women who complained of a variety of ailments unsubstantiated by medical examination and resistant to conventional medical treatment. Thus the beginning of psychoanalytic thinking and the presentation to the world of the unconscious and its influence on behavior.

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[2]. P 12, " Injuries that occurred in the front ('in Broca's area') left a person nearly mute, but able to understand everything that was said to him, while injuries that were further back ('in Wernick's area') left the person speaking fluent nonsense and unable to understand the speech of others".

[3]. Both men worked independently of each other.

Though overshadowed to some degree by the new science of psychanalysis, work on the brain and its function and disorders continued. Kraepelin a noted neurologist/psychologist in Germany, studied the illness Dementia Praecox (schizophrenia) and determined that it was a neurological disorder. He then set out to carefully chart and document behavior among the mentally ill patients in his hospital. Associated with Kraeplin at this time was Alzheimer who defined the specific kind of changes in brain cells which leads to the illness bearing his name 'Alzheimer's desease'.

Freud, in the process of developing his theories of psychosexual development, agreed with Kraepelin and acknowledged that the technology for adequately studying the phenomenon of dementia praecox was not yet available. Because of his training in neurology, he observed that many of the symptoms of the patients he attempted to treat, both in the hospitals of Vienna as well as in his private practice, were not of an organic nature. This marked his departure from traditional neurology and psychiatry.

He realized that a completely new science was needed, one that would explore and explain the workings of the mind embedded in the yet to be understood brain.

As mentioned by McFarlane, American psychiatry moved the emphasis of studying the illness away from the physiological/biological problem of the brain to the psychological and a problem of the mind. This had an enormous impact on the exploration and subsequently the understanding of aspects of schizophrenia.

Unfortunately, the refusal to see schizophrenia as a neurological/ brain disease has caused researchers to lose focus on the devastation of this illness not only to the person diagnosed as having the illness, but to every person and system of importance to that individual. In this regard we have failed to see schizophrenia and its relationship to other chronic illness. We have failed to give proper attention and recognition to the parents and families of the afflicted person for the burden imposed on them; instead we have assigned blame to them for the creation and maintenance of the illness.

THEORIES OF SCHIZOPHRENIA:

There are a number of theories regarding the etiology of schizophrenia. These theories can be categorized into conceptual frameworks or models which distill common factors among the related theories.

The Phenomenological-Existential Model; attempts to understand how schizophrenics experiences the world and their mode of existing. Incongruities in their experiences are seen as the possible root of their problem. Emphasis is placed on the here and now of the patients' experiences.

The Physical-Biological Models; focus on the possibility of biological imbalances that produce psychotic symptoms. These imbalances can be the product of toxic agents introduced into the body through a number of methods. Imbalances or the predisposition for imbalances of physical processes that are genetically inherited are also considered as a basis of the illness.

The Descriptive-Classification Models; are oriented toward the clinical observation, classification, recording and quantitative description of the phenomenon. Factor analysis and cluster analysis have been used to arrive at these classification categories.

The Conditioning-Behavioral Model; takes the position that schizophrenia is a manifestation of generalized inhibition and a disturbance in adequate response patterns. In other words, the illness is a result of undesirable conditioning.

The Sociological Model; focuses on the demographics of the illness. The Social Drift theory, which is well-known in sociology, postulates that certain conditions, such as poor urban settings, tend to attract and possibly generate schizophrenia.

Finally, within Social Work there are the two predominant theories: The Psycho-Biological and the Psychodynamic-Interactional model, both of which are outlined below.

The Psychodynamic-Interactional Model; as previously stated, this model is based on Freud's work with neurotic patients. Freud and many of his followers believed that schizophrenia was caused by deep, primary disturbances in the development and construction of the patient's mind and/or object relations. So deep were these disturbances that the prerequisite for psychanalysis, which is the ability to develop a transference neurosis, could not be met, thereby rendering the schizophrenic untreatable by Freud and his techniques. Another description of this perspective is the popular theory of schizophrenia postulated by the environmentalist neo-Freudians, (Klein, 1964). This view holds that deep disturbances in early object relations manifest themselves by a psychotic regression to the disturbed developmental phase when adult pressures exceed ego functioning and ability to adapt.

The Bio/Psycho/Social Model: Today there are a number of new assumptions about schizophrenia. These assumptions are based on empirical studies of brain structure and function[4] epidemiological studies, which include statistical data of prevalence, twin studies, and neuro-psychological findings.

The first assumption is that schizophrenia is not one disease but probably a group of diseases with different etiologies and quite different courses. Another assumption is that the schizophrenic has a basic deficit in processing information, paying attention, and modulating states of arousal levels or stress. These deficits have their origins in psychological, environmental and biochemical phenomena.

The temporal lobe and the limbic system of the brain have been identified as areas whose functioning is probably most effected by schizophrenia. The density and cell structure of this part of the human brain is different from every other high level mammal. It would seem that its function makes humans distinct from other

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[4]. The primary technologies are the CAT scan (computerized axial tomography, PET scan (positron emission tomography, BEAM (brain electrical activity mapping, MRI (magnetic resonance imaging and rCBF (regional cerebral blood flow). See Taylor, Edward H.. Social Work Vol 32, # 2, March-April.

mammals in that the temporal lobe is involved with receiving auditory information, the control of memory and language. It is also part of the "telencephalon" or "endbrain" which is the most highly developed of the brain structure.

The limbic system, located deep in the structure of the brain, plays an important part in the modulation of emotions. It is a complicated interconnection of various brain parts and circuits which define individual personality, cognitive style, and patterns of behavior.

The limbic system, along with the frontal lobe, is responsible for many executive mind functions such as thinking, evaluating, organizing and doing the things which make us human. These areas are the oldest part of the human brain from an evolutionary standpoint.

Studies have shown that damage to the limbic system in higher animals result in inappropriate and uncharacteristic behavior, emotional lability, perceptual problems and confusion. E. F. Torrey (1983) has stated that " abnormalities in the limbic system of human beings may produce... distortions of perceptions, illusions, hallucinations, feeling of depersonalization, paranoia, and catatonic-like behavior".

Some family history studies have shown that 90% of all schizophrenics do not have any family history of the illness. However, if one parent has the illness their offspring have a 15% chance of developing it. If both parents are schizophrenic there is a 45% chance that the offspring will develop the illness.

These statistics and interpretations are easily challenged both in terms of their accuracy as well as by psychoanalytically based theory. The parenting skills of someone suffering from schizophrenia would seriously affect the ability to provide a nurturing or "good enough" environment for their children. One's object relations could be seriously affected by the inconsistency and lability of affect, mood and responsiveness in a caretaker.

Studies of monozygotic and dizygotic twins provide firmer evidence in support of the genetic theories of the disorder. Since dizygotic twins are like any other siblings, and monozygotic twins are genetically identical due to the splitting of a single ovum, difference in the prevalence of the illness would be telling with regard to causes of the disease. Falloon reports "The pooled results of several studies reported in a recent review revealed a probandwise concordance for MZ twins average 45% whereas the concordance rate in DZ twins was around 15% (Gottesman & Shield, 1976; Falloon,1985)". This implies that there are genetic or biological variables which may be significant in the development of the illness as opposed to exclusively emotional or intrapsychic and interpersonal dynamics.

Autopsies of deceased schizophrenics reveal scar tissue and deterioration around the limbic system. These examinations were of individuals who were on psychotropic medication for long periods of time as well as those who were not. This provides some support to the slow virus theory and the notion of multicausal agents of schizophrenia. The slow virus theory postulates that the patient contracted a virus sometime around birth which took several years (up to onset which some where around 18 to 27) to show itself. The scar tissue is produced by the damage caused the virus.

There is a higher prevalence of schizophrenia among children whose mothers received spinal anesthesia during delivery. There is a higher prevalence of this illness among children delivered with forceps. There is a higher prevalence of this disorder among those born during the winter months, a time when infection is higher in the general public. These findings imply that one type of schizophrenia may be the result of a slow-acting virus or an earlier and minor damage to the brain which does not show itself until the brain has finally matured and has been activated to the fullest, as in the case of parts of the frontal lobe or limbic system[5].

With that position and the background presented above, it is reasonable to look at the presence of schizophrenia in a family much the same as one would look at the presence of Leukemia, or other debilitating chronic illness.

THE FAMILY AND SCHIZOPHRENIA:

Throughout history the family has always been the primary caretaker of the schizophrenic person. There are exceptions and variation, of course, but for the most part this has been the norm. With the advent of deinstitutionalization in the late 1950's

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[5]. The frontal lobe is the slowest maturing part of the brain. It does not go into full maturity and functioning until late adolescence or early adulthood. See footnote #34.

through the 1970's the family has become a focus of attention for researchers, clinicians and policy makers.

The family has been seen as a toxic entity for the mentally ill person based on predominant psychodynamic theories that heretofore dominated psychiatric thinking. Yet with the process of deinstitutionalization, most of the discharged patients returned to live with their families; and were accepted by them, Evans, Bullard, and Solomon (1961) reported that families did not abandon their mentally ill relatives as was popularly expected. Many families were willing and able, and did in fact, accept these patients. It has been demonstrated that families were also influential in many patients' effort to remain functional outside of hospitals (Freeman & Solomon, 1963). The sense of responsibility families seem to have toward their ill family member is clearly greater than was once thought (Uzoka, 1979).

Families have been involved in every aspect of schizophrenia. They have been blamed as well as praised for their influences in the problem. This project will attempt to understand another aspect of the family's relationship with schizophrenia. More specifically, what effect does schizophrenia have on the negotiation of life cycle tasks.

FAMILY STRESS AND COPING WITH SCHIZOPHRENIA:

It is well known that chronic illness has a powerful effect on families (Koch-Hattem,1987). Their ability to cope has been explored in a number of studies (Debuskey, 1970; Travis, 1976).

Unfortunately, most of these studies focused on the less stigma laden and more empathy-eliciting illnesses such as leukemia, heart decease, and cystic fibrosis (Debuskey, 1970). Research findings indicated families had to deal with shock, guilt, fear and confusion when faced with a chronic situation. The integrity of the family's structure and fabric are also heavily tested, especially when the afflicted child was young.

A number of studies have focused on the effect of chronic mental illness on the family. These studies illuminated the fact that mental illness created the same themes of burden and strain as did the less stigmatized and better understood chronic illnesses such as cancer, cystic fibrosis, ect. (Lam. 1979; Kreisman, Simmons, Joy, 1979; Doll,1976; Thompson, Doll & Lefton, 1977; Hatfield, 1978)[6]. This is a challenge to the notion that the family benefits in some primary or secondary manner from the patient being dysfunctional. There may be secondary gains for some, especially parents and family members who capitalize on the need to attend to the patient as a reason for not dealing with issues in their own lives. This is also true of non-mental chronic illness as well.

The burden of living with a mentally ill person can be viewed both in an objective or subjective way. Falloon, Boyd and McGill (1984) take the position that "...the objective burden of the

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[6]. As a reminder, many early family therapists believed the family benefitted from the emergence of symptoms in the identified patient. The presence of symptoms assisted the family in avoiding in a pathological way certain issues.

economic and social impact on family members can be assessed in terms of loss of potential earnings, additional costs of providing special care, disruption of the household routine, restriction of social and leisure activities, and physical and mental health problems".

In a very influential study, Hatfield and Lewin (1979), found that families were heavily subjectively burdened and stressed with the care of their mentally ill member. The subjects in this study registered feelings of grief, guilt, shock, bewilderment and helplessness. Despite these feelings, families continued to express a sense of responsibility and a desire to not abandon their ill family member. They expressed strong desires for help in coping[7].

The implication here is that the inevitable clash between the developmental needs of other family members and those of the schizophrenic will eventually intersect each other in a manner that is not normal in this cultures and is problematic to the successful negotiation of developmental issues for other family members.

SUMMARY

Schizophrenia was defined from a clinical, practice, historic and diagnostic perspective. It also presented a multi- dimensional

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[7]. The people in the Hatfield study listed the following needs as paramount. 57% understand symptoms, 55% specific suggestions for coping with patient's behavior, 44% relating to people with similar experiences,30% substitute care, 27% having patient change place of living, 18% More understanding from friends and relatives, 18% Relief from financial distress, 12% Therapy for themselves.

view of the phenomenon which sought convey the complexity and frustrations of those involved.

It is clear that researchers and practitioners alike are still in the dark about the illness. Part of the reason for the lack of clarity is the ongoing struggle between the proponents of various perspectives on the illness. Some evidence was presented which implied that a synthesis of several theoretical concepts is probably the track researchers and practitioners will eventually follow in treating the condition.

Finally the role of stress as it effects the patient as well as the family was outlined and given a significant place in the phenomenon.

CHRONIC ILLNESS

INTRODUCTION

The phenomenon of the chronic illness will be dealt with here. It introduces Rolland's typology of chronic condition and what is required of the individual and the family in dealing with each phase. This typology will also be used to gain perspective about the course of schizophrenia and how that course dovetails with the life cycle.

Schizophrenia, for about 75% of the people who are diagnosed as having it is a chronic condition. It is estimated that twenty five to 33% of all cases diagnosed as schizophrenic for the first time will not keep that diagnosis (Torrey 1983). Many people suffer one psychotic episode and never experience another. Others may have psychotic episodes but may not present the symptoms required to meet the DSM-III-R criteria for schizophrenia.

The chronicity of schizophrenia is no less and probably more devastating to an individual and burdensome to a family than any of the other less stigmatized, well known, and better understood chronic illnesses. There are several reasons for this, the most compelling being the fact that schizophrenia has no direct effect on a person's life expectancy. The sense of burden can be extended throughout the course of the illness, as well as the persistent feelings of guilt and hopelessness (Woesner, 1983).

The family and the burden of chronic illness is an area receiving considerable attention and scientific exploration.

Fortunately it has received a fair share of attention in terms of researchers and theorists outlining the coping and adaptation skills individuals and families find necessary in dealing with chronic illness,(Schmale, Ikel 1971), (Adams, Lindemann 1974; Davis, Quinlan McKegney, Kimball, 1973; Coelho, Hamburg & Adams 1974; Moos & Tsu, 1979; Deogatis, Adeloff, Melisartos, 1979; Moos, 1984; Penn, 1983). There is also a significant body of research in the area of chronic mental illness and the family. Most of these studies are under the general rubric of "family burden" (Mandelbrote and Folkard, 1961; Grad and Sainsbury, 1963; Hoenig and Hamilton, 1966; Herz, Endicott, and Spitzer, 1976; Hatfield, 1978; Thompson and Doll, 1982).

Research is still lacking in a number of areas. These areas include adequate exploration of the family environment, family interactions, and stages of family development. As a result, a number of untested beliefs about the families of the chronically person, and children in particular, continue to influence our thinking. The over-involved mother or the marital schism and/or skewing[8] can be easily labeled pathological even though that may be a misinterpretation of normal reaction to a stressful situation (Cummings, 1976; Cummings, 1966; McAlister, Butler, Lei, Paterson, 1973).

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[8]. Lidz et al. (1957b) coined the phrases. Marital schism is defined as a "state of severe chronic disequilibrium and disorder". Marital skewing is a situation where "serious strife was avoided because the dominant parent's seriously distorted ideas were accepted by a more normal but very dependent spouse, giving rise to a deviant and pathological family environment" (lidz. et al., 1958a,).

The high level of parental stress in dealing with a chronic illness is not only common sense but has been empirically demonstrated (Koch-Hattem, 1987; Gubman & Tessler, 1987). A number of studies focusing on marital satisfaction, marital tension, and divorce among couples when a child is stricken with a chronic illness, seem to verify that common sense perception (Korn, Chess, & Fernandez, 1980; Tew, & Laurence, 1975; Payne & Laurence, 1974; Walker, Thomas, & Russell, 1971).

Chronic illness is, in fact, a life crisis which puts the family through states of disequilibrium which may last throughout the life cycle. It is therefore reasonable to consider the cost of the illness to the family and their ability to negotiate developmental and life cycle tasks.

Since chronic illness is such a vast topic, most of the research has focused on the social (Bracht, 1979; Farkas, 1980; Mailick, 1979; Schoenfeld, 1981; Travis, 1976) medical, educational, and concrete services needs of the affected parties. Still lacking is a stronger emphasis of the dynamics and life stage issues of chronic illness.

CHRONIC PHYSICAL ILLNESS AND THE FAMILY:

The family life cycle is an important variable in the understanding of how families deal with chronic illness. When one considers family coping resources vary from stage to stage, the strain of caring for a chronically ill child[9] through a major portion of the life cycle can impose a costly burden to a couple and the family.

In attempting to better and more accurately understand the relationship between the family, its life cycle, and a wide range of chronic illnesses, Rolland (1987) suggests that a typology which categorize chronic illnesses is required.

Rolland points out that any typology is ultimately arbitrary. Therefore one is free to categorize not according to a predetermined rules, but according to the investigatory and intellectual need of the interested parties.

For this topic he takes the position that "Chronic illnesses need to be conceptualized in a manner that organizes these similarities and differences over the disease course so that the type and degree of demand relevant to psychosocial research and clinical practice are highlighted in a more useful way" (Rolland,1987).

Consistent with this position, various psychosocial typologies aimed at understanding the unfolding of chronic disease in a developmental context have been clarified by a number of theoreticians and researchers. (Beaver,1982), (Beaver, Voeller 1983).

Rolland's (1984,1987) typology of chronic or life-threatening

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[9]. I am using the word "child" to reflect the emotional perspective most often held by parents of schizophrenics. The onset of the illness in late adolescence tends to arrest the development of parents view of the patient. Forever they are perceived as they were last experienced as whole human beings.

illness addresses the problems of illness variability and time phases in two separate dimensions. In the first dimension the key biological similarities and differences that dictate the demands for the individual and the family are outlined. They are (1) onset, (2) course, (3) outcome, (4) degree of incapacitation of the illness.

(Onset)

Onset refers to the initial manifestation of the illness, which may be divided into two categorize: acute onset, which is sudden, unpredictable and unexpected as with heart attacks and strokes: and gradual onset, where there is warning, expectation, predictability and a recognizable process (i.e Diabetes, Alzheimer's, Parkinson or arthritis).

The adaptive skills and resources of the family are taxed by both types of onset. The acute onset requires a quick response, higher stress tolerance levels, greater flexibility, role interchangability, and efficient problem solving and communication skills. With gradual onset, the family has more time to adjust and must guard against denial, burnout, withdrawal or emotional over-involvement. Each form of upset presents different levels and forms of stress and challenge to the family struggling to maintain its functional integrity.

(Course)

The course refers to the qualitative, quantitative elements that characterize the illness after onset and before outcome. The course can be a progressive, constant or episodic/relapse. The progressive course is one in which the disease and its symptoms are incremental, such as cystic fibrosis. The constant course is one in which there is generally no progression of the illness and often no direct deterioration of the afflicted person's functioning, illnesses such as stroke and single-episode heart attacks are constant in their course.

The relapse/episodic course is characterized by alternating of stable and unstable periods, control of symptoms and acute exacerbation with varying periods of remission being typical. Multiple sclerosis, ulcers, shingles, lupus are illness that fall into this category.

The stress on the individual and family of each of these types is considerable and adaptive skills must be varied and extensive. Flexibility, stability, external support are required if successful development is to be experienced.

(Outcome)

Rolland (1987) defines outcome as "The extent to which a chronic illness will be a likely cause of death and the degree to which it can shorten one's life span". Therefore, one chronic illness will have no direct impact on the afflicted person's life span (such as arthritis), while others will have a profound impact on the life span (some forms of bronchial disorders, cancer and AIDS). Rolland points out that "For life-threatening illnesses, the ill member fears life ending before living out his/her "life plan" and of being alone in death. Family members fear becoming survivors and alone some time in the future. For both, there exists an undercurrent of anticipation, grief and separation that permeates all phases of adaption. Families are often caught between a desire for intimacy and a pull to let go emotionally of the ill member"(1987).

Families must struggle to maintain boundaries, perspective, problem-solving capabilities, integrity and responsibilities. For illnesses that may shorten the life span, over-protectiveness and the resulting secondary gains for the ill member are common.

(Incapacitation)

Incapacitation is the loss, disfigurement, reduction, of ability or added burden to the person or family as a result of the chronic illness. Impairment in mobility, sensation, cognition, energy and communication are among many things that can be directly affected by symptoms of a chronic illness. In the case of schizophrenia, all the above are likely to take place plus thought processes, perception and information processing difficulties.

Incapacitation can affect every facet of individual and family functioning. The hierarchical structure, instrumental resources, communication patterns, social supports, problem solving ability etc., may be affected by the incapacitation of the afflicted family member depending on who that individual is.

The phases of chronic illness are another dimension in

Rolland's typology. In the this dimension are the developmental time phases in the evolution or life cycle of the illness. The demands on the family struggling with a particular illness are affected by the requirements of the (1) crisis stage, (2) the chronic stage, and (3) the terminal stage. Each stage of the illness has its own tasks which require different skills and strengths on the part of the family and individuals.

(Crisis)

The crisis stage is the period following onset and generally before diagnosis and the development of a treatment plan. The family must learn to live with the illness and avoid putting family life plans on hold in order to accommodate the illness.

According to Moos (1984), the tasks for the family and individual are: (1) learning to deal with pain, incapacitation or other illness-related symptoms; (2) learning to deal with the hospital environment and any disease-related treatment procedure and; (3) establishing and maintaining workable relationships with the health-care team.

Other critical but more general tasks include: (1) creating a meaning for the illness event that maximizes a preservation of a sense of mastery and competence; (2) grieving for the loss of the pre-illness family identity; (3) moving toward a position of acceptance of permanent change while maintaining a sense of continuity between its past and future; (4) pulling together to undergo short-term crisis reorganization; and (5) in the face of uncertainty, developing system flexibility toward future goals.

(Chronic)

The chronic phase is the period after establishing a diagnosis and before the final phase of the illness. It is the period some refer to as the "long haul". During this phase, the individual and the family must tackle not only the biological aspects of the illness but the psychosocial ramifications it brings. The task is to maintain a sense of normality under abnormal circumstances through the day-to-day process of living with a chronic illness. Rolland points out that if the illness is progressive, a time of "living in limbo" exists for the family. For certain highly debilitating but not clearly fatal illnesses such as a massive stroke or dementia, the family can become saddled with an exhausting problem seemingly "without end".

(Terminal)

This is the last phase of any illness. It includes the realization of the inevitable loss, mourning and resolution of loss. The family must struggle with issues such as separation, death, grief, resolution of mourning and the return to a normal life.

Since schizophrenia is not generally thought of as a terminal illness, the physical death of the patient as a consequence of the illness is generally not an issue. However, it is not surprising that therapists know of elderly parents who feel that when their death is near they want their child to die with them or shortly before them. As a result of experience, many parents believe that no one will be able or willing to take care of their offspring. They fear that their child will be mistreated and suffer at the hands of others who are paid to care for them.

Penn(1983) points out that families or individuals can become permanently frozen in an adaptive structure that outlives its utility. For example, a parent may continue to cater to a child's demand for time and attention by responding to every beck and call when it is no longer necessary or adaptive. Thus the task of this phase is to continue to grow in response to the other areas of one's life and not allow the illness to totally dominate.

It is clear that each phase or dimension of Rolland's typology requires the individual or family to have a variety of skills, and resources if they are to successfully deal with the chronic situation. Each phase may occur during a different stage of the family's development.

ROLLAND'S TYPOLOGY OF CHRONIC ILLNESS

Table # 1

	Type of Response	Type of Skills Needed
Onset	Sudden/Crisis	Adaptability,Cohesion Communication
Course	Relapse/Episodic Chronic	Adaptability, Cohesion External Resources/Support
Outcome	Non-Terminal Terminal	Adaptability, Cohesion Instrumental Resources
Incapacitation	Permanent	All

SUMMARY

The parameters in which the phenomenon of having a schizophrenic offspring can be experienced was outlined. Rolland's Typology of the chronic situation also provides a framework from which the clinician and researcher can more clearly identify issues and phenomenon to be acted upon.

The responses from the parents in this study were analyzed with this typology in mind. That analysis proved to be very useful as it differentiated findings within and among groups which enlightened and confirmed previously held assumptions. Even though schizophrenia generally has a slow onset, parents realize that they are dealing with a serious illness which robs their child of many of the qualities enable him to enjoy the human experience. Consequently their reaction is similar to an acute situation despite the gradual onset of the process.

CHAPTER SUMMARY

This chapter attempted to present the literature (as of October 1991) and theoretical base of schizophrenia, the life cycle, and chronic illness as they pertain to the families in question. While it was not an exhaustive review it did funnel the issues and make the necessary connections between areas of study which here-to-fore were theoretically unconnected.

Taken in that context, it becomes clear how complex this situation is an how much additional attention it requires.

SECTION TWO

METHODOLOGY

CHAPTER II

PROJECT DESIGN

INTRODUCTION

The goal of this investigation is to examine how the presence of schizophrenia and schizoaffective disorders in a child, effect the ability of the parents and caregivers to negotiate their own life cycle and developmental tasks. Through the generation and analysis of empirical, qualitative data I hope to discover relevant information from which a theory or set of theories can be developed about schizophrenic patients and their families. The study is also intended to stimulate thought about the phenomenon of caregiving of this population as well give direction to future investigations in this area.

As reflected in the previous chapter, the sociological literature has provided an exhaustive body of knowledge regarding the family as a unit, its development and its structures. Family therapy has incorporated many of the theories and principles of sociology in its attempt to understand and better treat dysfunctional behavior in families and the individuals within.

A project aimed at exploring, describing and expressing the subjective experiences of the family's journey through the process seemed to be potentially valuable.

Such a project required willing and able subjects, and an accommodating setting in which to carry it out. Also required is an epistemology and a methodology which can do more that provide an antiseptic statistical analysis of quantitative data. A method is required which is conducive to capturing the experience of the subjects as they tell their own story.

This chapter will outline the methods of this investigation and describe the conduct of the study. I will briefly describe the subjects, the setting, and the logistical and procedural requirements for such an investigation. In addition, there will be a brief discussion of the relationship between the question asked, the epistemology and the methods employed in the pursuit of the subject's story.

EPISTEMOLOGY:

How parents negotiate developmental tasks or what effect does the presence of schizophrenia in a child and children have on the parents negotiation of life cycle tasks, are questions which go to the subjective qualitative, experiences of the subjects. They are inquiries which from a scientific point of view attempt to answer to questions about a "Social phenomena from the actor's own perspective".[10] (Taylor and Bogdan 1984, 2)

In order to properly answer such questions through rigorous scientific methods, a methodology consistent with the nature of the

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[10] The phenomenological perspective is related to the disciplines of anthropology, sociology, psychology, and linguistics. This perspective is associated with ideational theory in anthropology, including culture and personality theory, soceolinguistics, symbolic interactionism, and ethnomethdology. (Fetterman 1989, 16) Phenomenology is also a basis of the dramaturgical model, existential sociology, formal sociology, and a sociology of the absurd. (Taylor and Bogdan 1984, 12)

question must be identified. In order to choose a proper method of investigation the question must be elevated to an epistemological level. The process of selecting that method is described.

The positivist and the interpretive paradigm are the two primary scientific paradigms which offer social scientists the two dominant perspectives or ways of looking at the world. They also imply different scientific methodologies. Both are equally valid, despite the antithetical differences in philosophy and subsequent methods of viewing the world[11].

The positivist paradigm is currently the more popular and better understood perspective and determinant of the truth in research. The scientific methods used under this paradigm seeks to develop general theories or laws through a variety of means including stating theories, deducing hypotheses, and quantitatively testing the hypotheses. It is a philosophical position which supports the belief that through empirical studies the causal laws of social affairs can be discovered. It seeks cause-and-effect knowledge which promises to enable reasonable predictability of events and behavior. (Noble, Hare 1988, 12). In German idealistic philosophy which is credited for the development and propagation of the concept (Grinnell, 1985 p264) it is known as NATURWISSENSCHAFTEN. It is thought of as the "natural science" because its findings are also generally considered empirical and valid.

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[11]. Symbolic interactionism, is another way in which social affairs is looked at by social scientists.

Despite its popularity and acceptance as the producer of "hard data", the methods under the positivist paradigm do not meet the essential need nor do they adequately perform the tasks of this study. The methodologies of the positivist paradigm do not adequately develop an understanding or a sense of the subjects and their internal experiences in dealing with this particular situation. The limitations are primarily because methods of the positivist paradigm tend to statistically catalogue what the subjects has put out. With statistics one can report elicited responses which can be very different from the ongoing or general internal experiences of the subject. For example statistical methods may record the number of punches a subject throws but does nothing to understand the specific emotional state of the subject[12]. It does little to understand the fears, rage, sadness etc., the subject is experiencing. Nor does it tell how the subject came to choose one particular response to a particular situation, as opposed to another. (It does not comment on what it means to the subject to throw a punch).

Epistemologically these *How* and *Why* questions are in the interpretive paradigm[13] because they seek explanations of social and cultural events from the individual's perspective. These methods also tend to produce data and subsequent theory that is

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[12]. Another kind of data is required if one is to scientifically straddle the gap between what is "put out" and what is subjectively experienced by the individual.

[13]. Paradigm, according to Kuhn(1070) is "the entire constellation of beliefs, values, techniques, and so on shared by the members of a given community" (p. 175).

grounded in the persons everyday life.

The interpretive paradigm includes what the Germans refers to as GEISTESWISSENSCHAFTEN or the "science of spirit"[14]. This concept gives rise to the more appropriate methodology in pursuit of understanding as opposed to the acquisition and accumulation of the truth or laws regarding a particular phenomenon. The interpretive paradigm or perspective attempt "to make sense of an object of study...to bring to light an underlying coherence" (Taylor, 1982: 153) to what is being studied or explore.

It is widely believed among social scientists that the answers to *How* and *What* questions are best attained through the extraction of data from qualitative research methods. Yin (1984) suggests that qualitative methods " are the preferred strategy when *How* and *Why*[15] questions are being posed, when the investigator has little control over events, and when the focus is on contemporary phenomenon within some real life context" (p 13).

Strauss and Corbin (1990) take the position that:

> these questions by nature lend themselves more to qualitative types of research. Because they...
> attempt to uncover the nature of persons experiences with phenomenon like illness.

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[14]. According to Grinnell, there is no literal English translation for the word Geisteswissenschaften. The closest translation is science of spirit which is the alternative or the opposite of Natural Science. It is very much as legitimate as the Natural Science and another way of understanding the world.

[15]. As a clinician I am in the habit of using "What" instead of "Why". I will continue that practice here out of personal preference, and professional choice. "What" is used instead of "Why" in clinical and therapeutic settings because of the accusatory connotation of "Why". "Why tends to put people on the defensive and inhibits the free and un-edited flow of information.

This study focuses on the perceptions, experiences, and subjective realities of the parents as they live and have lived with schizophrenia and C disorders.

During the last two decades the social scientific community has changed its perception of qualitative research methods and techniques[16]. The data produced was once and to some extent is still seen as soft data. However that point of view does not reflect the appreciation many researchers have of the substance and the differences in the type of knowledge the method produces. There was a perception that the data did not conform to strict, reproducible, scientific methods that confirm the data. In other words there have been questions of the validity of the data and the reliability of the methods used.

Jones defends qualitative methods researcher's handling of the validity issues in the method by indicating that:

> Qualitative methods are not simply a few techniques to gather data; they encompass a whole host of assumptions, concepts, questions, and hypotheses as well as an orientation--a way of looking at the world, ascertaining what is significant, seeking meaning, and creating understanding (Jones 1988, 47).

The facts or the truth are pursued quite differently with the qualitative methods than with quantitative methods. Qualitative data which is properly generated and analyzed not give a limited two dimensional, stagnant, snapshot portrayal of a phenomenon. Instead it provides a dynamic, multi-dimensional, hologram, with

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[16]. In fact Miles & Huberman reminds us that "Anthropologists wondered out loud whether researchers in other fields are reinventing the wheel(Wolcott, 1980)" (Miles & Huberman, 1984 P15).

depth, process, context and color.

Many practitioners such as Social Workers and Nurses have a healthy appreciation for what qualitative methods have to offer. They seem more aware that the:

> "...dimensions of human experience are constantly changing and cannot be studied using the objective principles of quantitative research methods (Filstead, 1979; Watts, 1976).

Qualitative data significantly adds to the knowledge that is vital to their practice because, unlike social researchers who look for facts, truth and laws, social practitioners such as Social Workers and Nurses are accustomed to dealing with "Wicked Problems" which cannot easily be understood or resolved. They require multi-dimensional diagnoses as well as multi-modal solutions.

Further support for qualitative research methods in the pursuit of multi-dimensional data is espoused by Strauss and Corbin (1990, 17) who say that:

> Qualitative methods can be used to uncover and understand what lies behind any phenomenon about which little is yet known. It can be used to gain novel and fresh slants on things about which quite a bit is already known. Also, qualitative methods can give the intricate details of phenomenon that are difficult to convey with quantitative methods (Strauss & Corbin, 1990 17).

Qualitative methods, however, are not without shortcomings. As mentioned before, the methodology brings with it problems of reliability and validity. Miles and Huberman ask the question:

> How can we be sure that an earthly, undeniable, serendipitous finding is not, in fact, <u>wrong</u>? (Miles authors emphasis).

One of the compelling reasons that this question is asked is because, as they point out, qualitative methods have no..."shared ground rules for drawing conclusions and verifying their sturdiness" (Miles & Huberman, 1984).

Due to the lack of standardization, qualitative data has generally not been taken as leading to truth. For some it was at best interesting anecdotal material about an individual phenomenon. The truth as it is commonly known has to be redefined to include more than it is generally understood to mean under the aegis of qualitative methods. Taylor and Bogdan tackle the issue and states that:

> the issue of *truth* in qualitative research is a complicated one. What the qualitative researcher is interested in is not the truth per se, but rather perspective.

Miles and Huberman echo this concern and explain that qualitative research's methodological problems are rooted in the fact that:

> Qualitative studies are rich in descriptions of settings, people, events, and processes, but they usually say little about how the research got the information, and almost nothing about how conclusions were drawn.
>
> The problem, of course, is that we can't verify or do secondary analysis of a study in which procedures are so opaque. We are left with vague criteria: the plausibility, the coherence, or the compellingness of the study--all evocative but ultimately hollow terms. The researcher can always provide a plausible account and, with a careful editing, may assure its coherence. If the writing is good, we will be won over by the undeniability and vividness of the report. But,... plausibility and coherence accounts can be terribly biased, and vividness lands us in the availability heuristic, whereby we overweight concrete or dramatic data (Miles & Huberman 1984,).

Perspective can be achieved with certain constructs according to Lincoln and Guba (1985, 290-296). These constructs are applicability, consistency, and neutrality of a study: credibility, transferability, dependability, and confirmability.

It is clear that the methodological problems of the qualitative research are considerable in terms of acceptability and reproducability of data. For some time a number of qualitative researchers have been trying to remedy this situation by devising systematic methods of conducting research to contribute to the systematizing, synthesizing, and analyzing of data. Many of these methods and techniques are outlined by Miles and Huberman (1984) in their book Qualitative Data Analysis: A Sourcebook of New Methods.

A number of other ethnographers such as Wolcott (1990), Fetterman (1989) Strauss & Corbin (1990), have welcomed the arrival of computerized methods of qualitative data analysis. The development of (Wolcott,1990), software programs such as THE ETHNOGRAPH, QUALPRO, ANTHROPAC, and TAP (TEXT ANALYSIS PACKAGE), which are designed for data management with personal computer have further validated qualitative methods. These computer software programs are currently available to many researchers in the field (with laptop units) as well as in "the office".

Wolcott is amazed at the ease, versatility, and range of data coding and manipulation computer programs offer the ethnographer. Miles and Huberman cite some of the benefits of computerized data management methods and how it helps with the issue of reproducability. They state that such software programs:

> show special promise, since the analytic steps and procedures used can be easily recorded, displayed, and shared with other researchers. (Miles and Huberman 1984,, 248).

Despite the obvious need for the qualitative methods to continue to evolve, it is also important to keep them from becoming a bastardized version of quantitative methods. Fetterman states that it is important that:

> The ethnographer recognizes the importance of understanding the epistemological basis for a selected model. The typical model for ethnographic research is based on a phenomenological oriented paradigm. The paradigm embraces a multi-cultural perspective because it accepts multiple realities. People act on their individual perceptions, and those actions have real consequences-thus the subjects reality each individual sees is no less real than an objectively defined and measured reality (Fetterman 1990).

This study employs both qualitative and quantitative methods in a manner supportive of each other. Both retain epistemological and methodological integrity which add to the validity and value of the data produced. However, it is important to keep in mind that this study is primarily a qualitative one which gives the parents of a few schizophrenic patients an opportunity to tell their story.

GROUNDED THEORY/ETHNOGRAPHY:

The types of qualitative methodology employed in this study can be labeled "ethnography" and "grounded theory",. These two techniques are closely related to and supportive of each other. The distinction is subtle yet significant to the character of this study's questions and the data sought. The first format refers to the qualitative method which is a basic approach to discovering data within the interpretive paradigm. It is a method of gathering data and understanding the phenomenon the data reflects. It seeks to look at a situation from the inside out or epistemologically speaking attempts to gain the *emic* perspective[17].

The Grounded Theory, is a theory- building method that systematically develops theories about a particular phenomenon by letting new knowledge or questions emerging out of the qualitative data that have been compiled. Through the application of Grounded Theory to qualitative data an inductive theory about a phenomenon is developed which can influence further investigations or offer a new slant on an issue. An accepted definition of a Grounded Theory is that it:

> is one that is inductively derived from the study of the phenomenon it represents. That is it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore data collection, analysis, and theory stands in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge (Strauss & Corbin, 1990).

The hope and expectation guiding this study is to provide a richer understanding of the subjects' experiences and to influence policy as well as individual treatment planning.

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[17]. The emic perspective--the insider's or native's perspective of reality--is at the heart of most ethnographic research. The insider's perception of reality is instrumental to understanding and accurately describing situations and behaviors. Native perceptions may not conform to an "objective" reality, but they help the field worker understand why members of the social group do what they do. In contrast to a priori assumptions about how systems work from a simple, linear, logical perspective--which might be completely off target--ethnograph typically takes a phenomenomogically oriented research approach.

As emic perspective compels the recognition and acceptance of multiple realities. Documenting multiple perspective of reality in a given study is crucial to an understanding of why people think and act in the different ways they do. (Fetterman, 1989, 30-31).

COMBINED METHODOLOGY:

Even though qualitative methods dominate this study, quantitative methods bring an important addition through a set of standardized qualitative and quantitative interviews.

Combining quantitative and qualitative methods is valid and advisable in many situation including this one. In this study, they are used to understand how the caregivers of patients suffering with a chronic and little-understood set of mental disorders such as C and schizophrenia disorders, cope with them. It seemed important to understand how stressors are interpreted and behaviorally addressed by the subjects. Scientifically they may also be used to support and enhance each others data (Strauss, Bucker, Enrlich, Schatzman, & Sabshin, 1964.). To do so, the following must be considered:

> The "multi-site, multi-method" (Smith & Louis, 1982) effort can be very effective and persuasive if it is carried out in a formalized and compatible manner (Herriott & Firestone, 1983).

The transcripts of the interviews will provide a picture of the *emic* perspective. That is to say it will illustrate the internal qualities of the subjects' experience. According to Fetterman, "an 'emic' perspective compels the recognition and acceptance of multiple realities". He goes on to say that:

> Documenting multiple perspectives of reality in a given study is crucial to an understanding of why people think and act in the different ways they do. Different perceptions of reality can be useful clues to individuals' religious, economic or political states and can help a researcher understand maladaptive behavior patterns (Fetterman 1990, P32).

The quantitative measure F-COPES was employed to reflect the coping behavior patterns of the subjects in dealing with certain life stressors. It offered the *"Etic"* perspective which is the: "External, social scientific perspective of reality" (Fetterman, 1990 P32). By combining information elicited by both methods which tap both the *emic* and the *etic* perspective, a richer more comprehensive contextual picture may emerge which will make more sense of the situation.

SETTING:

This study was conducted at the Baltic Street Clinic which is one of seven community mental health clinics of South Beach Psychiatric Center. South Beach Psychiatric Center is a large psychiatric hospital which is part on the Office of Mental Health of the State of New York.

The Baltic Street Clinic is located in Southwest Brooklyn and is mandated to provide psychiatric services for one of the most socially, ethnically and economically diverse areas in the New York City Metropolitan area. The general census of the Baltic Street clinic is approximately 380 outpatients. A wide variety of diagnostic categories are represented here. Both the patient population and the community at large probably have as diverse a socio-economic makeup as any community of comparable size in America.

SAMPLING:

The study consisted of 30 families. The decision to have an N of 30 was based on my desire to control the number of transcript pages I would have to code and analyze. Thirty was also a reasonably rounded number, considering the surprisingly limited number of patients who meet all the criteria for inclusion in the study.

Even though the diagnosis of schizophrenia or schizoaffetive disorder are the most common in the clinic, many patients who had these diagnoses did not meet other criteria to be included in the study. They and/or their parents may not have spoken English or their parents may not have been alive or available.

Those are some of the personal and logistical reasons for the decision. The methodological reason is simply that there is justification for having only 30 subjects. Grinnell's (1985) statement that:

> "Some professionals have made the case that in order to use basic statistical procedures the sample size must be at least 30, but more conventional wisdom suggests a minimum sample size of 100".

Furthermore, my knowledge of the population and the planned method of analysis also influenced my decision which was also supported by Grinnell's view that:

> "These guidelines must be qualified, however, because sample size is affected by knowledge about the population and the extent of categorization of the sample necessary in the analysis of data".

Initially a stratified random sampling procedure was employed in the selection of subjects. It was chosen primarily for its appropriateness for studying multiple strata or categories such as the three stages of the Carter and McGoldrick's family life cycle.

Stratified random sampling is a method which employs simple random sampling procedures. In such sampling, each person in the population is assigned a number. A table of random numbers is then used to select a number from among those assigned each member of the population such as 1 to 500. Features of the randomly selected number (such as each randomly selected number that is odd less than the first number) is then used to select the remaining members of the sample.

The stratified sampling method repeats this process until each stratum or category the researcher hopes to investigate has the pre-determined and/or a statistically acceptable number of subjects, or in this study's case, when the pool of candidates has been exhausted.

This method was chosen because of my desire to have equal representation in each of the three developmental categories being studied. In addition, there were other cells such as ethnicity, family constellation etc. to be filled. According to Grinnell, (1985), in selecting this form of sampling the investigator:

> "assures that a sufficient number of cases with each diagnosis will be included in the sample to permit the desire analyses".

However, due to unexpected circumstances, this sampling procedure had to be abandoned because of insufficient number of available subjects with whom the three developmental categories or strata could be filled in equal numbers. For example, the first stage four, *The Family with Adolescents,* had only two subjects,

The following is a more detailed description of the sampling procedure as it eventually evolved.

PROCEDURE FOR SAMPLING:

The sampling procedure began with the identification of every patient on the Baltic Street Clinics' census who has a diagnosis of schizoaffective or schizophrenic disorders. There were 216 patients diagnosed as having either of these conditions. Each patient's diagnosis is determined either by the admitting clinician or the current treating person. The diagnosis is based on the presenting symptoms which determines the appropriateness of admission. This diagnosis serves a number of clinical, administrative and financial functions including determining private insurance reimbursement eligibility.

Because a patient's diagnosis is not and in many cases ought not be static if treatment is proceeding or successful, that diagnosis should and can be updated and changed from time to time to reflect the patient's most current mental state and diagnostic picture. This means that there are patients in the clinic's census who were or may in the future present symptoms which may cause their clinician to consider them schizophrenic or C. There are others who may have fit the diagnostic category at the time subjects were being recruited but their clinician may not have changed the diagnosis on the diagnostic sheet. Those individuals were not included even if they were being treated as though they had either of the illnesses.

Technically the opposite should also be true. The sample may contain individuals who are not or are no longer considered schizophrenic or C. However, after going through each case I am confident that the process might have erred on the side of omission but not on inclusion. The validity of each diagnosis was scrutinized by a thorough review of the subject's history and clinical course.

After the list of all patients with these two diagnoses were compiled, the list was put in alphabetic and numerical order. Once this list was made up, the next step was to ask each therapist to identify any patients who should not be approached and asked to participate. This was done out of clinical consideration for the patient and courtesy to the individual therapist. Many therapists still subscribe exclusively to the psychodynamic and psychoanalytical methods of treatment in which the sanctity of the exclusive relationship and the resulting transference must be honored at all costs. Interference with that process might not be in the best interest of the therapeutic process or more specifically the patient's stability.

Beginning with the first name on the list, every seventh patient was selected to fill each of the three developmental categories. (The number seven divides into 216 with a remainder of six. Therefore seven became the sequence setter for the sampling process). The age of the selected parent then determined the developmental category that each subject was put into.

The corresponding chronological age of the parents to the three developmental cycles was dictated by Neugarten (1968). He indicated that in the working class, middle age is considered to begin at 35 and old age at 60, because of the emphasis working class men place on physical strength and vigor. On the other hand, the middle class whose jobs and life style tend to be more cerebral and less dependant on physical performance, tend to consider 45 as the start of middle age and old age and 70 as the beginning of old age.

The decision to use Neugarten's demarcations were partly out of convenience and the fact that his parameters were as reasonable as any that included chronological ages for their developmental stages theories.

This subject selection process was continued until the master list was divided into seven groups of thirty names and an eighth of six. I then processed each name beginning with the first name on the first list until there were thirty willing and appropriate subjects. This process continued through the last name on the last list.

Patients were then eliminated from that list based on the following criteria. Patients were eliminated if their parents spoke a language other than English or Spanish[18]; if the patient's

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[18] One interview was conducted with the assistance of a Ph.D Clinical Psychologist who served as a Spanish interpreter for me. This Psychologist was familiar with the subject and his mother. She was also familiar with this project and the subject matter. She understood the type of information I was interested in and attempted to not only translate the words but convey as many of the nuances of the responses as possible.

parent's or primary caregivers were no longer alive; if as mentioned above the therapist felt the study would somehow interfere with the therapeutic process.

Those who went through the first round were then asked if they had any objections to their parent/caretaker being asked a few questions about their lives and how they deal with certain issues. If there were no further objections parent/caregivers were contacted either in person or by telephone. They were told the purpose of the study and they were read the consent form which answered anticipated questions[19]. If they declined they were thanked and nothing more was asked of them or the patient. As the consent form indicated, they were reassured that their refusal to participate in the study would in no way have any negative effect on their family member's ability to continue receiving treatment at the clinic.

If they agreed to participate, arrangements were made for the interview to be conducted at their convenience. In many cases the interview took place immediately after the subject gave verbal consent and the consent form was signed. In other instances the consent form was sent to the subjects who signed and returned it before the interview was conducted by phone.

Only two subjects refused to participate. Their reasons were similar. They did not want to upset things in the home. They were not pressed to explain their vague statements and reasons.

Of those who consented, one may speculate as to why they were

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[19]. See consent form in appendix

so willing. This phenomenon will be discussed further in the findings and discussion section of this paper. However, it is worth noting at the point that the cooperation of the subjects may be attributed to a number of factors including my familiarity with the clinic's schizophrenic population and their familiarity with me. Another factor could have been my role as an administrator as well as the possibility of some confusion in their understanding of the purpose of the study[20]. I believe some of the subjects thought they were being asked to participate in a South Beach project as opposed to a study which was sanctioned by South Beach.

The interviews were conducted at a number of sites. The site was determined by the subjects and conducted at their convenience. Two interviews were conducted in the home of the subject; 9 were conducted in my clinic office and 15 were conducted over the telephone with the assistance of a speaker phone which allowed the interviews to be audiotaped. Of the 15 interviews conducted by phone, six were done from my home, and seven were done in the clinic office after working hours. One parent refused to be audio taped. He also could not find time in his schedule to come to the clinic or have me visit him in his home or some other convenient place. That interview is not as detailed as the others. However, I managed to record many of the salient points of the interview.

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[20]. In my function as a therapist, and an administrative overseer of the intake and admissions process, I have come to into contact with many of the schizophrenic patients and their families in one form or the other.

The length of the interviews varied from as little as 30 minutes to as long as one hour and forty-five minutes.

LIMITATIONS OF THE SAMPLE:

The sample was made up of people who lived in the catchment area of the clinic. Because the clinic and the hospital to which it is affiliated is a State facility, the patients and families who served are generally of the lower middle class to poor economic categories. The upper-middle class or wealthier population is not represented in this sample. The minority population is over-represented, especially the English speaking Hispanics. The educational level of the caregivers is probably close to representative of the national population.

Many patients are on some form of public assistance whether it be AFDC, SSI, SSD, Workmen's compensation, and Medicaid or Medicare. Exclusively Spanish-speaking patients and their parents are not represented. This is a major limitation since they represent a significant segment of the urban population with special stressors and social and economic limitations. Information about how they handle and succeed at these developmental tasks would be another area of inquiry worth pursuing.

SUBJECTS:

The subjects in this study were the parents and primary caregivers of 30 patients with a diagnosis of schizophrenia or C disorder. The patients were selected from the general census

(Approximately 380 patients) of the Baltic Street Clinic of South Beach Psychiatric Center. (See demographic chart for more detailed information).

The Parents:

Thirty caregivers or caregiver constellations participated in this study. They ranged in ages 38 to 79. The mean age was 60.5 16 were single parent and 2 were headed by single men. The estimated income level of the family is within the range of 0 to $40.000 (See demographic data chart on page 80 for additional information.) Twelve parents or caregiver's were gainfully employed at the time of the interview. Only four patients were employed in any form at all. All four felt tremendous gratification and shoring-up of their self esteem from being employed, even in a sheltered situation. Two have demonstrated a real potential to be completely self-sufficient at some time in the future.

The Patients:

Twenty-four of the thirty patients were male. Four were female. Only one patient was married; she currently lives with her husband. Seventeen were diagnosed as having a mental illness more that 10 years ago. Twenty of the thirty patients currently live with their families. Of those who do not all but two have regular contact with their parents. Two lived in a residence or some form of supervised housing. Twenty-six patients have siblings, and of those, fifteen still living at home. Only one patient had a sibling who has been diagnosed as having a major mental illness. Two have siblings who also suffer from a mental illness or some other chronic illness. For patients the mean number of hospitalizations was four. The range of hospitalizations is 0 hospitalization, as in the case of four patients who were never hospitalized, to more than 15 in one case. Four were hospitalized as frequently as 10 times, one had 12, three had 9, and the rest ranged from two to eight.

Demographic Chart:

Table #2

Variable		Stage IV	Stage V	Stage VI	Combined
			PATIENTS		
AGE					
	N:	2	11	11	24
MALES:	Range:	20- 21	22-44	31-42	20-44
	Mean:	20.5	27.36	35.6	27.82
	N:	0	2	4	6
FEMALE:	Range:	0	30-39	26-70	26-70
	Mean:	0	34.5	43	38.75
			PARENTS		
	N:	0	8	4	11
Fathers:	Range:	0	52-64	63-78	52-78
	Mean:	0	59.75	69.6	64.6
	N:	0	2	4	6
Mothers:	Range:	38-43	46-63	56-79	38-79
	Mean:	40.5	60	66.4	57.3
ETHNICITY					
	Black:	2	4	6	12
	White:	0	7	6	13
	Hispanic:	0	1	3	4
	Other:	0	1	0	1

THE INSTRUMENTS:

The Questionnaire:

Two sets of instruments were used in gathering data for this study. One was an original instrument developed specifically for this study and the other was the F-COPES, a standardized quantitative family coping instrument with acceptable validity and reliability ratings.[21]

The original instrument developed for this study is a twenty-seven item open-ended survey questionnaire which was administered by the interviewer. Its primary purpose was to serve as a guide in the interviewing process. The questionnaire touched on a wide range of issues within the realm of the subject matter which might seem unrelated when viewed as separate components or issues. However, all of the questions are part of the same "semantic or cultural domain" Weller and Romney (1988) define the semantic or cultural domain as:

> simply the subject matter of interest, a set of related items. it...may be defined as an organized set of words, concepts, or sentences, all on the same level of contrast, that jointly refer to a single conceptual sphere (Weller & Romney, 1988).

That is to say, they are all questions touching on various

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[21]. According to Fredman & Sherman (1987), "Internal consistency reliability estimates for the final instrument were: acquiring social support, .83; reframing, .82; seeking spiritual support, .80; mobilizing family support to acquire and accept help, .71; passive appraisal, .75 to .95 for other subscales, and .81 for the total inventory".

Validity: "Although factor analysis did demonstrate the existence of five independent concepts, no other validity data are reported other than the surface appeal of the items".

aspects and issues of life cycle tasks and parents' response to them when a child has schizophrenia or C disorders.

The relevant theoretical constructs and issues which were opened for exploration by the questionnaire included the well documented phenomenon among families with schizophrenic members, STIGMA and BURDEN (Mandelbrote & Folkard, 1961; Simmons, 1963; Grad & Sainsbury, 1963; Hoenig & Hamilton, 1966; Stevens, 1972; Creer & Wing, 1974; Hoenig, 1974; Herz,E ndicott, Spitzer, 1976; Hatfield, 1979; Thompson & Doll, 1982;), Rollands' TYPOLOGY of ILLNESS, 1987[22], The EMOTIONAL PROCESS OF TRANSITION: KEY PRINCIPLES of Carter McGoldricks' fifth and sixth stage of the family life cycle[23], and Combrinck-Grahams CENTRIPETAL CENTRIFUGAL concepts of family life cycle viscidities.

Most of the questions were phrased to allow the respondents to elaborate or to be as brief and/or specific as they wished, for example, question number six asks, <u>On a scale of one to ten how independent do you feel your child is at this point in his/her life"</u>? Other questions clearly conveyed a desire on the interviewers part for a more elaborate and expansive responses. For example, question number twelve asks, "What are some of the major concerns for you as a parent at this time in your life"? Or "Tell me how you feel about the way your child turned out".

The questions were arranged in a manner which started with the

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[22]. See literature review chapter.

[23]. Stage #5. Launching children and moving on, Stage #6 The family in later life.

most benign (Fetterman, 1989) and gradually progressed to what seemed to be the most provocative and emotionally unsettling. For example, the first question was, How old were you when you got married? and the last question was, Is there anything you would like to take care of before you reach that point?. Questions also followed the chronological order of the life cycle which for this study's purpose starts with the marriage of the couple and ends with death.

Despite the appropriateness of the questions in terms of content, there were a number of deficiencies in the questionnaire which did not become clear to me until data collection was completed. Still more limitation were revealed during the data analysis. Some of these deficiencies included the phrasing of some of the questions. Instead of using the adverb "how" so frequently, I could have posed questions much more open ended with phrases beginning with words such as "Tell me how...".

As recommended by Fetterman I should have started the questionnaire with "survey question" which would have allowed the respondents to paint as general and non-threatening a picture as possible. On this point Fetterman says ..."survey question-is designed to elicit a broad picture of the participant or native's world, to map the terrain". The survey question would " predominate in the early stages of fieldwork, and more specific questions in the middle and final stages" (Fetterman, 1990, p51)... of the data gathering process. My questionnaire started with a very specific inquiry "How old were you when you got married"? and proceeded with varying degrees of specificity and generality and a gradual increase in degree of emotional difficulty.

Pre-Testing The Questionnaire:

The instrument that was used in this study evolved from a questionnaire that was much cruder, more cumbersome, lengthy and un focussed. A number of questions were eliminated after first pre-testing with a number of individuals who were not registered as patients of South Beach Psychiatric Center but met all protocol requirements. Following the first pre-test, further refinements were made and they were similarly tested on two subsequent occasions. The final pre-test took place with three families of patients who were registered at the Baltic Street Clinic.

All three sets of parents were patients of mine with whom I had worked at least four years up to that point. They had been exposed to the current treatment of choice for schizophrenic patients and their families. As a result of their psycho-educational treatment they were familiar with these issues and were able to provide feedback about the questions from both sides of the treatment process.

A fourth family was part of the final pre-test process. This family did not know me as a therapist nor were they familiar with the psycho-educational method of treating schizophrenia. I was reasonably sure that they had not been asked these questions by their regular therapist nor had they dealt with these issues in any overt way.

The pre-test families signed consent forms but were not included in the final N of thirty. The pre-test interviews were video taped but not transcribed for analysis. The video tape was reviewed to determine the usefulness of each question, as well as similarities and consistencies in their responses.

Through this process questions were rephrased, edited, and eliminated. The final product was used in this study. I also decided to not use video tape. Following the recommendation of Dr. Mailick, I decided to use audio tape which proved to be much more useful and convenient.

The F-COPES Instrument:

The other instrument used, the F-COPES (The Family Crisis Orientation Personal Scale), is a rating scale instrument developed by McCubbin, Olson and Larsen. It measures internal and external strategies used by the family in response to problems or difficulties. It is comprised of five subscales which, according to Fredman and Sherman(1987, p200), is more useful than the total scale. In terms of reliability, the internal consistency reliability was .83 for acquiring social supports; .82 for reframing; .80 for seeking spiritual support; .71 for mobilizing family to acquire and accept help; .63 for passive appraisal; and .86 for the total scale[24] .

There was no time limit for completing either of the

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[24]. These are the subscales which when used separately seem very useful to the practitioner or researcher according to Fredman and Sherman (1987, P200).

instruments. The authors of the F-COPES indicated that the instrument takes about 10 minutes to complete, and this proved to be the case in the present study.

F-COPES Scoring:

The F-COPES instrument was divided into five sub-categories, social support, reframing, spiritual support, mobilizing family support and passive appraisal. Scores were determined by adding the rating score each respondent gave for each statement in a particular sub-category. If a particular category has four statements and the respondent strongly agreed with each of them, a score of 5 will be assigned to each statement and 20 (5x4) for the category. If they strongly disagree, they assigned a score of 1 to each statement producing a minimum score of 1x4 or 4. It they neither agreed nor disagreed with the four statement they will assign a score of 3 for each statement and the categories central score will be 3x4 or 12.

THE INTERVIEWING PROTOCOL AND STRATEGIES:

Every research study has at least one vehicle upon which it largely depends for its data. In the case of this study the vehicle (Ethnography) not only provides data in the appropriate form; it contributes heavily to the definition of the methodology. According to Fetterman(1990, p47), for the person involved in ethnographic research the interview is the most important data gathering method. He states that the:

> Interviews explain and put into a large context what the ethnographer sees and experiences. They require verbal interaction, and language is the commodity of discourse (Fetterman, 1990 p48).

A formal structured interview format was the primary method for eliciting data from the subjects. This method of interviewing was selected over other ethnographic interview methods because of the nature of the questions asked, and the range and depth of responses being sought. It is a method which is consistent with maintaining boundaries, limiting the universe and maintaining the context in which the phenomenon is being studied.

It also allows the respondents the freedom to expand, specify, enhance, package, and tell their story as they wished it to be heard and understood. At first I believed on some lower emotional and intellectual level that all I should have to do was wind the subjects up with a good and specific question and they would do the rest by providing all the relevant broad and specific data needed.

I failed to recognize the full value of the interviewer as the primary data gatherer who must use his/her presence and skills to elicit information. I failed to recognize at that time what Taylor and Bogdan emphasize which is that the interviewer is:

> ...far from being a robot-like data collector, the interviewer, not an interview schedule or protocol, is the research tool. The role entails not merely obtaining answer, but learning what questions to ask and how to ask them". (Taylor & Bogdan 1984, p77).

What I was fully aware of however was that the structured interview method also approximates and is best suited to a research study with a specific goal in mind. I did understand and chose this format because the formal structured interviews can also:

> "generally serve comparative and representative purposes-comparing responses and putting them in the context of common group beliefs and themes" (Fetterman, 1990, p48).

This form of interview is therefore appropriate because of my intention of looking at three subgroups within the larger sample.

Even though the F-COPES instrument was not designed to elicit qualitative responses but to give a quantitative response, the subjects were not discouraged by the interviewer from elaborating or explaining how they felt about a particular matter. Therefore, the former cautionary comments were applicable to the administration of the F-COPES instrument was well.[25]

Following the reading and re-reading of the consent form, I explained the interview process as well as the use of the audio tape to the subjects and proceeded to read the questions from the questionnaire.

In the case of the telephone interviews the subjects were asked to trust that no one else was within hearing distance of the speaker phone through which the cassette recorder was taping the conversation. Only one subject refused to be recorded. As detailed as possible, dictation was done during the interview and transposed immediately after the interview to recapture as much of what was actually said as possible.

The F-COPES instrument was administered immediately after the completion of the Life Cycle Questionnaire. I asked the questions

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[25]. Even though the subjects were aware of the differences between the two instruments, they continued to respond to the F-COPES questions much as they did with the Life Cycle Questionnaire. They had to be reminded to give me a quantitative response as the instrument required.

and recorded the responses on the response form. The audio cassette for each interview was saved as another precaution against lost data.

DATA ANALYSIS PROCEDURES

As with the interview protocol and strategies, my understanding of the ethnographic process did not begin to mature until I was well into the process and already beyond a few very important stages. Miles & Huberman's book Qualitative Data Analysis (1984)., magnified and underscored what I had been taught but had not fully processed and understood about this methodology.

In ethnographic research the analysis of the data (Wolcott, 1990) begins at the moment data has been collected (Miles & Huberman 1984, p50). Even though it is not a requirement, it seems wise to begin the analysis of the data at the earliest possible point. Rendering the whole experience of the subjects is the raison d'etre of doing qualitative research and ethnography in particular.

Data analysis during the collection process can help the:

> ...field worker cycle back and forth between thinking about the existing data and generating strategies for collecting new-often better quality data; it can be a healthy corrective for filling-in blind spots; and it makes analysis an ongoing, lively enterprise that is linked to the energizing effects of fieldwork (Miles & Huberman 1984, p49).

Because data analysis during the data gathering process allows the researcher to fine tune the design and the methodology as needed, it maximizes the probability of getting the true *emic* perspective of the subject given the design is appropriate.[26]

Miles and Huberman also takes the position that ethnograph researchers' failure to analyze data during the gathering process is:

> ..."a serious mistake. It rules out the possibility of collecting new data to fill the gap, or to test new hypotheses that emerge during analysis; it tends to reduce the product of what might be termed "rival hypotheses" that question the fieldworker's routine assumptions and biases; and it makes analysis into a giant, overwhelming task that both demotivates the researcher and reduces the quality of the work produces" (Miles & Huberman 1984, p49).

That mistake was almost committed in this study. However, the power of the process prevented that error from being made as evidenced by the descriptions to follow.

DATA DISPLAY:

Because this study contains both qualitative and quantitative data, a conscious decision was made to have three parts to the description of the method of analysis. The first part will describe the qualitative method. The second the quantitative, and the third will describe how both methods were used to augment, support and sometimes challenge each other.

Since the aim of this study was to learn if and how subjects

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[26]. Miles & Huberman also takes the position that an ethnograph researchers failure to analyze data during the gathering process is a ..."serious mistake. It rules out the possibility of collecting new data to fill the gaps, or to test new hypotheses that emerge during analysis; it tends to reduce the product of what might be termed "rival hypotheses" that question the fieldworker's routine assumptions and biases; and it makes analysis into a giant, overwhelming task that both demotivates the researcher and reduces the quality of the work produced" (Miles & Huberman 1984, p49)

traverse the three identified theoretical life cycle stages despite the presence of the stress of caring for a schizophrenic offspring, it seems reasonable that the structure and process for analyzing the data be guided by the second order changes of each developmental stage. The data will be presented in that format as well.

The second order changes are those specific and behavioral activities the individual and the family must accomplish in order to succeed in the transition from stage to stage.

The questionnaire was designed to reflect all of the second order changes within the three Carter & McGoldricks life cycle stages, stages IV, V, and VI. The data will be presented in narrative form with the help of the respondents' verbatim accounts of their experiences in this developmental process.

In addition to the focus on the tasks of the three life cycle stages, the issues of onset (Rolland, 1987), adaptability, and flexibility were examined at in terms of their significance to the respondents' experience (Olsen). Once again these issues will be presented on their own as well as in their relationship to other variables in the study.

The following is the step-by-step account of the analysis of the qualitative data.

DATA REDUCTION:

Data reduction, is the process of transforming raw data into a form which can be manipulated and systematically analyzed. In this study it was a process which not only prepared the raw data for analysis but, as I came to realize, it was an integral part of the analytic process. My experience was substantiated by Miles and Huberman's position that:

> "... Data reduction is not something separate from analysis. It is part of analysis. The researcher's choice of which chunks to code, which to pull out, which patterns summarize a number of chunks, what the evolving story is, are all analytic choices. Data reduction is a form of analysis that sharpens, sorts, focuses, discards, and organizes data in such a way that "final" conclusions can be drawn and verified. (Miles & Huberman, 1984 21, authors emphasis)

The following is the systematic process which led to the theories and conclusions to be discussed later. As previously stated, the data influenced the analysis at various intervals during the process.

Transcription:

After all the interviews were conducted, the 29 audio tapes and one written record which made up 30 interviews were transcribed into an IBM AC comparable Premier 1400 286 computer. The word processing program used to do the transcribing was the WordPerfect 5.1 . Transcribing was done by the investigator over a period of several weeks. The task was assisted and made more tolerable and manageable with the use of Dictaphone on loan from the study cite.

The Dictaphone machine allowed me to control the speed of the audio tape. It allowed alternation of the speed of each word spoken to pick up each syllable should distinguishing it at the subjects normal speaking speed be difficult. This option was also used when the subject could not be clearly heard or understood.

Each individual interview and the one document encompassing all 30 interviews were saved both in the hard drive of the computer and on one 3 1/2 high density floppy disk. The floppy disk copy was designated a back up should the hard drive in the CPU, (Computer Processing Unit) become defective. Each document was labeled with the first name of the patient and number of the order in which the interview was conducted, this resulted in 30 moderately-sized and one large document.

A verbatim transcription of the intereviews were done with all the accompanying verbal sounds described in one form or the other. I am referring to verbalizations such as "ah" and "ha" or "sniffle" when there were tears and other visual indicators of emotion.

In order to use The Ethnograph's qualitative software package, the documents had to be converted to an ASCI file which allowed the software to read and perform necessary analytic manipulations[27]. After several attempts to understand how best to use the program, (which is very user friendly if the instructions are followed), I decided to use one large document for data analysis instead of the thirty individual and separate interviews. Using the larger document simplified matters as well as took advantage of the program's data analysis capabilities.

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[27]. Both Susan Bernstein a recent Hunter College School of Social Work DSW graduate and John V. Seidel a co-designer of The Ethnograph were very helpful in getting me past the ASCII conversion road block which held me up for a considerable amount of time.

Coding:

The next step in the data analysis process was the coding of the data. With the use of the NUMBER DATA FILES command the document was coded in a manner which allowed the thirty interviews and each response within each interview to be differentiated. Sixty-two hundred and fifty-eight lines of data were numbered and made ready for further coding and analysis.

Prior to entering and booting up The Ethnograph software program, a list of codes was developed which would identify preconceived concepts and issues which are appropriate to the stages of the life cycle being investigated. For example, the code RN represented "the renegotiation of marital systems and dyads", B=burden etc(See list of codes). This list was also composed of theoretically required tasks, events and processes as outlined by the theoretical concepts which also dictated the study's questionnaire. These codes came out of developmental issues and tasks described by Carter and McGoldrick, in "Second Order Changes in Family Status Required to Proceed Developmentally", Rolland's "Typology of Chronic Illnesses", and Combrinck-Grahams Centripetal and Centrifugal concepts of family oscillations.

The numbered document was re-read several times to "get a feel" for the data. The concepts and issues that emerged during the process were then coded in addition to the pre-determined issues and concepts listed above. Some of these observations were pessimism, hope, positive attitude etc. In all there were 86 different codes representing 86 different observations. One of the strong features of The Ethnograph software is it's D function. The D function allows multiple coding, which means that any single line or group of lines of the document may have as many as seven distinct conceptual codes assigned to it. As a result the 86 separate codes were used in various combinations throughout the document.

To conceptualize what that might resemble, one must visualize a five line paragraph. To the right of the paragraph and beginning on the first line there could be a bracket which encompasses the first three lines. It extends from line one to line three. That bracket would be coded, let us say, H for the expression of hope. From lines two to five is another bracket which extends further out into the right margin than the first and is coded G for guilt. A third bracket could begin on line two and end on line four and be coded B for burden. This process continues until there are seven layers of brackets over this single paragraph.

As mentioned before these seven layers of bracketed codes were used to create categories, code my observation and generally tried to extract meaning from the data. However, the constellation of codes in certain paragraphs and sections were in themselves revealing.

DATA CATEGORIZATION AND DISPLAY:

With this capacity available, I continued to manipulated the data in a number of ways to get a sense of what was in the transcript. The data were separated and compiled according to question, subjects, and conceptual issues of which there were many, and a variety of other variables. If I wished I could have printed out 86 documents with the statements of each code. Instead, I printed out every response from each subject for each question on the questionnaire. For example, when I wanted to look at when the caregiver first noticed the patient was or becoming symptomatic, I was able to see as one printout the response of every subject to that question. If there were two related questions or a spillover from one question to the other, I was able to cull only those responses.

For example, I was able to see responses to questions number 5, 6, and 7, and get the broader context in which the statement occurred. The responses may automatically include responses 5,6, and 7. This kind of specificity and differentiation was possible for every code and every variable identified in the document.

The next display of the data was having the software program present the frequency with which each coded concept appeared in the transcript for individuals, the three developmental stages and the entire sample as a whole. The sequence of frequencies, which is the flow from the most frequently observed issues to the least frequently observed issues, were then generated and examined. Once again each developmental stage was studied independently of each other and comparisons were made among stages as well as the entire sample population. This analysis revealed some very interesting patterns which will be reported in the findings chapter.

ISOLATED AND INDEPENDENT ISSUES:

The next step in analytic process was to look at isolated and independent issues such as Olsen and McCubbins concepts of adaptability, cohesion and flexibility, and Rolland's psychosocial typology of illness as it related to onset. These variables were looked at in terms of frequency of appearance in the transcript, their significance to the subjects and their role in the developmental process.

QUANTITATIVE DATA ANALYSIS:

The F-COPES instrument is a simple rating scale instrument which was designed to access a family's use of coping strategies when faced with problems or difficulties in their lives. According to Fredman and Sherman(1987) the F-COPES instrument:

> ...is a 29-item, five-point self-report inventory that measures internal and external family strategies. The internal strategies are the ways family members deal with crisis by using resources within the family such as confidence in problem solving, ability to face changes, and passive, inactive behaviors. External strategies include active behavior the family use to acquire resources outside the family system, such as religious resources, relatives and grandparents, friends, neighbors, and community resources.

All of these resources were separated into five categories which, according to Freman and Sherman(1987), are more useful as sub-categories. Freman and Sherman(1987) recommend using the instruments subscales because:

> The subscales show greater promise for therapy and research that the total scale.
>
> The total scale although moderately reliable, contains

> items that seem, at least conceptually, to belong to different worlds. "Believing if we wait long enough, the problem will go away" and "Seeking professional counseling " are both coping techniques. What does it mean when two such different items are added together to produce a total score?

In following that recommendation the total scale broke down into the following sub-groups, Acquiring social supports(9 questions), reframing(8), spiritual support(4), mobilizing family resources(4), and passive appraisal(4 questions).

In terms of what they actually represent, Social Support is defined as the ability to try to get help from relatives, friends, and grandparents. Reframing is the ability to redefine crisis to make them more manageable. Spiritual Support is simply the utilization of religious officials such as priests, rabbis, shamen. Mobilizing Family To Get Help, like spiritual support is self-defined. It is simply mobilizing family to acquire and accept help. Passive Appraisal is the ability to ignore problems and minimize reactions.

The instrument used a one-to-five Likert Scale for scoring. A response of one indicated that the respondent strongly disagrees with the coping method suggested. Two meant they moderately disagreed, three meant they neither agreed or disagreed, four was moderately agreed and a five indicated the respondent strongly agreed with the coping strategy.

The responses were scored and the data categorized in a number of forms. As with the qualitative data the results were manipulated and analyzed with a number a questions in mind. These forms and variables included the three life cycle stages, marital status of the caregivers, ethnicity, etc..

The scores and their significance revolves around a central or neutral score for each of the five subcategories on the scale. Table number 3 lists the central/neutral scores for each of the five subcategories. A neutral or central score in the F-COPES scoring is the score which indicates the respondent has no strong opinion one way or the other regarding a particular coping question and method.

The neutral numerical score is arrived at by circling 3, the numerical equivalent of the choice "Neither agree or disagree", on the N,X response form. All of the circled numbers represent the response choice of questions in each category. They are then summed up. For example, the spiritual support sub-category has four questions with a central score of 12 (a score of 3 times 4 questions=a central score of 12). If a respondent moderately agreed that his/her family used all four methods they would score 4x4x4x4 or a raw score of 16. A score of sixteen indicated that the parent or family more than "neither agree or disagree" because their score would be sixteen.

NEUTRAL OR CENTRAL SCORES OF F-COPES CATEGORIES

Table # 3

PATIENT #	SOCIAL SUPPORT	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRAL.
	C=27	C=24	C=12	C=12	C=9

C is the central score for each category

Any score below any of these neutral numbers indicated the respondent either strongly or moderately disagreed with the F-COPES statements. Any score higher that the neutral numbers indicates the respondent moderately or strongly agreed.

A chart was developed in which the subject's number or scores for each category were placed on the Y-axis and the particular variable of interest was placed on the X-axis. The score for each question was then written into the grid and a score summed up.

The scores from the F-COPES instrument were then used as a launching point for further analysis, interpretation, support, framing and reporting of the data.

Based on the trends, scores, and impressions from the data, a narrative was produced which included direct quotes from the respondents which told their story in both a scientific and narrative manner.

Each patient in the study was rated for their current level of functioning. The rating scale was taken directly from DSM-III (The Diagnostic And Statistical Manual). DSM-III rates patients level of functioning from 1 to 7 for clinical purposes. On this scale a score of 1 represents superior functioning which is, according to DSM-III, "Unusually effective functioning in social relations, occupational functioning, and use of leisure time". A score of 7 represents "gross impairment in virtually all areas of functioning"[28].

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[28]. The entire scale can be seen in the List of Scales.

COMBINED QUALITATIVE AND QUANTITATIVE METHOD OF ANALYSIS:

Each data analytic modality highlighted separate issues within the data. Both raised different questions which were not further investigated, and each was used to support as well as challenge the implications of the other.

The method of analysis here is fairly simple and straightforward. Where appropriate the data was used exactly as described above.

Finally, the analysis and presentation of findings will begin at the onset of the phenomenon and the point from which these subjects become different from the general population. Even though this was not the original intent, the data compel the reorganization of the method of presentation.

MECHANICAL MANIPULATION OF QUALITATIVE DATA

As indicated in the methodology section, after the subjects were interviewed their responses were transcribed with the help of an IBM clone personal computer and the Word Perfect word processor program. The software program, The Ethnograph, was used to code and manipulate the qualitative data which permitted analysis of its content in a relatively simple and manageable manner.

One of the simpler and more powerful manipulations was the generation of a frequency list of code words from subject responses. The coded words were a combination of pre-determined words and issues such as burden, and flexibility, as well as those issues and observations which emerged as the document was repeatedly read.

The software, The Ethnograph, allowed a number of other manipulations of the data. This program's flexibility assisted in examining some variables alone as well as in combination.

The next manipulation performed was the separation of the subjects' responses by question. In other words, I was able to get a printout document of every subject's response to question 1 through 27. I was also able to obtain all the responses of all the subjects to any code. Not only could I get a list of each subject who expressed fear or any other variable I coded, but I was also able to obtain the context in which the statement or observation was made.

This analysis produced mountains of paper and almost endless combinations of statements. Despite the shear volume, the organization of the data by the software program made it very manageable. In the final analysis, I believe I used only a portion of the software capacity.

This process involved the entire sample of thirty subjects. It was then repeated for each of the three life cycle stages. The result was four sets of data which were structurally identical in that they all had a frequency distribution of coded words and observations. There is also a list of responses by each subjects according to questions on the questionnaire. Also available was a list of various combinations of responses which together produced an enormous amount of data which was looked at in a variety of ways and combinations.

Data from each modality, including the F-COPES instrument, will be used as both primary and supportive presenters of issues depending on the power of their suggestion and whenever, appropriate. However, the qualitative data will dominate simply because that is the nature and strength of this study.

The analysis will begin with the a most compelling observation, which is the frequency list of coded words for each life cycle stage as well as the entire sample. This observation and all issues coming out of these observations will be presented in terms of both the individual life cycle stages and the entire sample. Inter and intra-variable comparisons will also be made according to the dictates of the data and the keenness of observations.

The next stage in the qualitative data analysis was the dividing the questions in the questionnaire according to the three life cycle stage tasks which influenced their composition.

The responses to the questions and the story they tell will be presented within the appropriate life cycle stage starting with The family with Adolescents followed by Launching Children and Moving On, and finally The Family In Later Life.

Finally, where relevant and useful, an overall analysis and comparison of responses will be made. Data from F-Copes will be included in this process as well.

However, the data will first be analyzed in terms of four separate but none the less important variables which are now associated with the condition. These variables are burden, adaptability, flexibility, and the time of onset of the illness. These issues were targeted with specific questions in the questionnaire, and will serve as launching points for understanding the role of these variables in the lives of the respondents.

CHAPTER SUMMARY

This chapter outlined how the study was designed and conducted. It described the relevant philosophical perspectives such as the interpretive paradigm which validates scientific methods seeking to develop an understanding of a phenomenon from the participants subjective point of view. This chapter also distinguishes the interpretive paradigm from the positivist paradigm which is more popular and generally better understood because of its ability to produce hard, quantitative data.

Finally the combination of these two paradigms was also illustrates as I sought to use each perspective to support or challenge the other's findings. A description of the population, setting, instruments and method of data analysis were also described.

SECTION THREE

FINDINGS

CHAPTER III

PERTINENT VARIABLES

INTRODUCTION

This chapter presents the findings of the study in terms of the three specific life cycle stages with which schizophrenia is associated. These stages are *The Family With Adolescents, Launching Children and Moving On, and The Family in Later Life.* In the Carter & McGoldrick's life cycle model, specific changes in family status are required in order to accomplish the tasks of each stage.

The tasks of *The Family With Adolescents* are a) Shifting of parent child relationships to permit the adolescent to move in and out of the system. b) Refocus on mid-life marital and career issues. c) beginning shift toward concerns for the older generation. For *Launching Children and Moving On*, the tasks are a) Renegotiation of marital system as a dyad. b) Development of adult-to-adult relationships between grown children and their parents. c) Realignment of relationships to include in-laws and grandchildren. d) Dealing with disabilities and death of parents (Grandparents). And finally the life cycle model, *The family in Later Life.* The tasks are, a) Maintaining own and/or couple functioning and interests in face of physiological decline: exploration of new familial and social role options. b) Support for a more central role for middle generation. c) Making room in the system for the wisdom and experience of the elderly; supporting the other generation without over-functioning for them. d) Dealing with loss of spouse, siblings and other peers and preparing for death. Life review and integration.

These tasks and the accompanying and required changes are presented and discussed in terms of the respondent's personal experiences in their attempt to negotiate them.

The data to be presented consist primarily of verbatim responses of the subjects to specific questions about specific developmental tasks. Quantitative data provided by the instrument F-COPES will be used to supplement, challenge and clarify the respondents' responses as well as the researcher's observations and interpretations.

The instrument F-COPES is a Likert type 30 question instrument which attempts to access the subjects use of social supports in response to stressful situations.

Special emphasis will be placed on four issues which emerged as prominent variables in this study, and their significance to the phenomenon as a whole. These variables are: flexibility, adaptability, burden and onset. These outstanding variables will be presented starting with onset followed by flexibility, adaptability and burden respectively.

ONSET:

The question, <u>When did you first notice that your son/daughter might be having mental problems?</u> was asked with the Rollands(1987) concept of "onset" in mind. It was also the most logical point at which to begin to gather data about the impact of schizophrenia on the lives and the negotiation of life cycle issues of the respondents. It was also intended to identify the place in the life cycle stage with which the couple or family were dealing at the time the illness was introduced into their lives and demanded attention.

It is important to note that the question did not ask, when did the patient first exhibit symptoms? Instead, it inquired as to when parents experienced the onset of their child's illness. In retrospect this semantic distinction proved to be very significant and revealing. Although this finding was not anticipated, it provided this research project with one of its most important findings.

The time frame of parents responses were surprisingly wide in range and significance to the impact on their adaptability and the quality of their lives. This is an extremely important phenomenon in light of Rolland's position that the different forms of onset of a chronic illness require different degrees of mobilization of family resources and strengths (Rolland 1987). Rolland also takes the position that being able to mobilize family resources is necessary for the successful handling of chronic illness. Studies have shown that when a family is not functioning properly it can have negative effect on the course of an illness. Thus it can prolong symptoms and or make them worse (Minuchin et al, 1975, Manuchin, Rosman, & Baker, 1978).

The more acute the onset of a major and chronic illness, the less time the family has to mobilize its resources. The less time they have to mobilize their resources the more stressed, less appropriate, less rational, less comforting and well thought out their responses will be.

According to Rolland:

> Illnesses can be divided into those that have either an acute onset, such as stroke, or gradual onset such as Parkenson's disease. Although the total amount of family adaptation might be the same for both types of illness, for acute-onset illness these effective and instrumental changes are compressed into a short time (Rolland, 1987).

One can hypothesize that parents who experienced the onset of their child's illness as acute would have felt more stressed than those who did not. However, of thirty parents interviewed, the overwhelming majority (27 out of 30) described a gradual onset of their child's illness in the same fashion as Rolland (1987) defines onset. *But their <u>experience</u> and response to the onset in terms of their affect, awareness, problem solving ability, adaptability and use of available resources was more in keeping with an <u>acute onset</u>.*

For example one mother recalled that her son, a promising artist seemed fine until he entered high school. Her description of her experience was more akin to an acute onset as apposed to what the historical facts reveal as reflected in his clinical chart. She remembers that:

> ...Bernard was in H.S., he had become withdrawn and you know, being a very, now let me see, he was very outgoing and *all of a sudden* he became very withdrawn and didn't like to go out.

The patient was not forced to leave his room or interact with other members of the family. His behavior was not challenged. At first his withdrawal was not noticed nor was his increased religiosity and auditory or visual hallucinations. When his parents finally noticed his increased isolation, they attempted to normalize it by attributing it to transitional behavior between adolescence and manhood or his increased closeness to God.

His parents finally "caught on" when he began to "all of a sudden" in his mother's words act bizarrely in front of dinner guests. Shortly thereafter he became very disruptive and began to destroy property in his room. He eventually became agitated as his auditory hallucinations made him believe Jesus Christ was talking to him through the television. He eventually became frightened of the voices he heard, and images he saw on the television. He became destructive and needed to be hospitalized. In reality his decompensation took several months and was not an acute onset as perceived by his parents.

The parents of another young male patient, Jon, reported that:

> ...There was no specific time that he was a problem or whatever...But it was a time when my mother was sick and there was a lot of depression. A man had called me to go down to the street, I called them (her older children) up and told them the situation with Jon. I really didn't think anything was wrong, my daughter came up and told me Jon was drinking in the street.

The patient's bizarre behavior which was first attributed exclusively to drugs and alcohol abuse did not abate in the following hours and days. He eventually began to act on his bizarre thoughts and internal experiences which included Satanic ritualistic behaviors and statements. He eventually lost control and began to bang his head on the walls of his room. He was subsequently hospitalized.

In gathering additional personal and family history through the treatment process, Jon revealed that he had been smoking pot for a long time before the precipitating event. In fact Jon was symptomatic for several years and attempted to medicate and suppress some of the disturbing, confusing and annoying things he felt were happening to him. He was depressed, unusually suspicious of others, had ideas of reference in that he believed that the behavior of those around him (including what they said to other people) was really directed to him. In other instances he believed the actions of others had direct and significant bearing on his life. He also heard faint voices but they had no faces. He rationalized those experiences as either residuals from the pot smoking or an overactive and punitive conscience.

In retrospect, it is clear that the patient had exhibited numerous and obvious prodromal signs prior to the precipitating incident. It is also clear that a lack of knowledge about the illness, and the presence of other stressors within the family appeared to have interfered with their ability to perceive clues of the illness and to respond more quickly to the situation.

As alluded to in the first case example, a common reason for this lack of response and awareness that something was wrong with the patients, was the common notion that in our society bizarre and unusual behavior is expected, tolerated and sometimes glorified when exhibited by adolescents. Unfortunately its inaccuracy has not made it less popular.

One mother who shared these beliefs recalls her experiences at the onset of her son's illness:

> ...well it was that Casper at those times was around 28 years old and the other child was 15 and I realized something was wrong with Casper because he used to hit the second child, beat him up and I didn't know what to do. The youngest child left the house and went to a gang and he got into trouble with the gang because of Casper beatings. And finally something happened in the gang that they wanted to kill him Casper and that is why he had to leave home at that time. It was before that I began to realize that... How when he finished high school he was ok. Then he began the university. Then he served (studied) for two years than quit college. At that time there was some problems he used to punch the walls, the doors, I didn't understand. I knew about mental illness and I noticed that this is weird behavior but I thought perhaps it was something that boys do or it's his personality.

This was yet another effort to "normalize" the behavior of the patient.

Another set of parents explained away their son's difficulty with concentration and social discomfort (paranoia) as the manifestation of his low intelligence. In response to the original question the father of this patient says:

> ...Ohhh I would say maybe at age 8,9,10,11,12, or so, you know. It's hard to say it could have been later it could have been 14 or 15 he went to school he was slow in school.

Of the three parents who gave accounts of the onset of their child's illness, none had any conscious recognition of any prodromal symptoms.

The most glaring example of this "normalization" or denial reaction was found in the case of Lori. Lori was a 33-year-old woman who was brutally beaten by her drunken husband "up and down the street" where she lived and had grew up. According to this patient's mother, her daughter was a wonderful normal woman, wife and mother who made a terrible mistake of marrying a man who drank too much and seemed to have different values from her own.

The precipitating event in Lori's first official psychiatric break was a merciless beating at the hands of her drunk, unemployed husband in the street on which she grew up and currently lives. As a result of the beating she sustained several bruises, cuts and a concussion for which she was hospitalized. She remained hysterical and emotionally unstable longer than the medical staff expected someone in her condition to be. It became apparent that psychiatric treatment was indicated and the patient was introduced to the psychiatric community and she was diagnosed as schizophrenic at the relatively advanced age of thirty three.

It took a terrible event such as the one described above to break the massive denial and normalization that this family employed for several years. Prior to the incident, her family saw her as perfectly normal. The fact that she was married and had a child reinforced their delusion and denial of her condition. The patient would spend much of her time looking for work. Her manner of dress for these employment interviews reflected an awareness of the need to dress for success. However, her attempt to toe the mark of the general standard was negatively affected by her inability to attend to detail such as not having catsup on her lapel, or making sure that her blouse was buttoned properly.

She would spend her time going into Manhattan only to aimlessly ride the subway in a psychotic and delusional state. She would then return home to report on her job hunting experience.

The family continued this "dance" for several years not noticing or admitting to the realities of the Lori's situation. The benefits of this massive delusion were abruptly interfered with by the beating Lori received. The family seemed as angry at the abuse Lori received from her husband as they were about being told that she was mentally ill and had a diagnosis of schizophrenia. In fact her mother was very angry and said in response to being told the diagnosis:

> I never noticed it till she was beaten up by him, she was a nice girl, she was independent, working and taking care of her son and her household...I guess that's what every mother thinks of their children, daughters especially... Now she jumps at me whenever I have something to say... she doesn't care to sit with me.. she's always talking about Jersey, those Jersey people, I don't know what that meant to her.

For several years this mother and the rest of the family were able to deny the presence of Lori's auditory hallucinations. They knew that she believed there was a girl in the walls of her bedroom who spoke to her every night. This girl would age ten years a night until she became an adult only to return to her infant state to begin the cycle all over again.

Another parent clearly remembers his son becoming symptomatic after an accident. He says:

> Well he was in an accident. He got hit by a car while playing a game in the streets. He was in college at the time.

The most dramatic and obviously very traumatic situation of acute onset was with a parent who is himself diagnosed as having schizophrenia but was a very high functioning schizophrenic, a man of constant good spirits, pleasant and steady disposition abruptly replied to the question... And remembers when his own son first became ill:

> Oh when his sister got killed, that was in 1984. He was fine before that, no problems.

Prior to that incident the patient was allegedly free of any signs of mental illness. I should point out that the patient's mother does not suffer from mental illness, but has a physical disability with which she is appropriately preoccupied. She also reported the same facts as her husband. The parents other child is a bright young woman who is currently in college. She corroborated her parents account of the situation.

Despite the fact that the rate of onset was gradual for the overwhelming majority of patients, the gradualness of the onset did not seem to be any less traumatic for the family when "it hit them" that there really was something wrong. *The realization that there was something seriously amiss seemed to have been experienced as an acute onset.*

These parents, and probably most parents of schizophrenics' do not, and did not have the normal experience of suspecting that something identifiable was wrong, followed by a visit to the doctors who may have ordered tests, explain what was going on and give concrete instructions as to how the condition can be treated etc. Nor were they given a hypothesis about the condition. Instead the assault of the incomprehensible behavior caused them to clam up and become defensive. The lack of information about what they were dealing with did not allow them the lubricant necessary for flexibility and successful adaptation. *Instead they all required an extremely disturbing and wrenching event to realized their child was ill.*

According to Rollands' typology of chronic illness and the life cycle the:

> Families that are able to tolerate highly charged affective states, exchange clearly defined roles, flexibility, problem solving efficiently and use outside resources will have an advantage in managing acute-onset illnesses (Rolland 1987).

It is clear to this writer that flexibility is an important element of this phenomenon. It would seem that if a family unit is to be successful in negotiating life cycle tasks, flexibility is essential. This notion is partially supported by the fact that issues of flexibility occurred most frequently occurring issue in the subjects' responses.

FLEXIBILITY:

Rolland espoused flexibility as an essential ingredient in the successful response to major and acute chronic illness or to the perception that one has to manage a chronic illness.

Flexibility was the most frequently mentioned theme among the 30 subjects. However, the subjects who were in stage IV, *Families With Adolescents*, it hardly appeared as an issue. Among the subjects in Stage V, *Launching Children and Moving On*, it ranked third, preceded only by independence and burden. In the final life cycle stage, Stage VI, *The Family in Later Life*, was by far the most frequently occurring issue. It seems that as a family ages, issues of flexibility become greater. This may be due to the fact that as one gets older resources and options tend to lessen and one's adaptation seem to depend on their flexibility.

Flexibility as an issue was coded only twice among the parents in stage IV. This suggests that it may not have been any more important or pressing an issue for them than fear, pessimism and family closeness, all of which were coded with the same frequency as flexibility. It also seemed to be less important to these parents at this stage of their lives than the parents in the other two life stages[29].

When flexibility appear in the responses of the parents in stage IV, it was as descriptive and reflective of their own personality traits as it was of the family's functioning and relationship. One mother speaks of experiences with her sons as well as her self-evaluation around this issue.

In response to the question How flexible do you feel you are as a parent, and as a husband or wife? Her reply was:

> I would say I'm flexible in some areas and then I'm very rigid in others.

She goes on the give examples of her flexibility and rigidity:

> Oh well I expected him to grow up into you know he always said he was interested in medicine and that was his first choice and then after now he said he was going into music which Ken (his therapist) and the doctor feel well I'm a bit to ambitious. I should leave him alone and not try to steer him back into that course.

In another situation she demonstrates what happens when she

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[29]. There will be additional information and analysis of these findings later on in this presentation.

asks her son to do something. She says:

> My general method is I get aggravated and annoyed and I just end up doing it myself so I think I'm like that at my job also. If I ask someone to do something and they constantly renege and not get it done, I'll just pick it up and you know do it myself. To me it's less exasperating to just get it done and do it myself.

She believes she has changed over time, she says:

> I think I've become more flexible.

Flexibility as an issue and operative concept was prominent among the parents in STAGE V. Many of them responded to question thirteen and sixteen which is Have you become more or less flexible over time?

Many simply responded to question thirteen by saying:

> It took a long time.... Because I am able to see and understand a little bit more about how "M" is and also you know she had to understand how I am. O yes I'm much more flexible.

Another parent says:

> How flexible? As a parent well, I know during the years I have become more flexible... more experienced and what not.

And more candidly:

> I wasn't very flexible as a wife. I'm more flexible as a mother.

Yet another:

> Well my children oh, I'm pretty flexible with them. Of course my children are all grown now. I don't have any babies that I have to deal with, you know young ones. I'm very flexible with them as far as their going and comings, you know with what they want to do, I don't really stand in their way.

And then:

> Very flexible. As a parent not so much in all aspects for there's certain things in the aspect of life that I

consider that degrading.

The respondents' concept, emotional access and use of flexibility appears to change and expand as they get older and go from one life cycle stage to the next. The increased flexibility seems to be partly a by-product of experience with a chronic illness and partly access to resources. However, the lack of resources seem to decrease flexibility and increase the sense of burden.

BURDEN:

The issue of family burden has been established as one of the most important issues in the area of schizophrenia and chronic illness (Grad & Sainsbury 1963, Creer & Wing 1974, Hoenig 1974, Hatfield 1979). This seems to be especially true in terms of its effect on the course and outcome of conditions. It is a phenomenon of major interest not only to the patient but to the family as well. It has the potential to influence the manner in which the family is viewed by others. This is true whether or not it is from a personal, familial, social, economic political, or spiritual perspective.

During the coding and analysis of the data it became obvious that the issue of burden was present in responses to just about every question asked. Throughout the family life cycle burden continues to remain virtually unchanged. Burden is the second most occurring variable among all respondents. It ranks number one with Stage IV, number two with Stages V and VI.

It was expressed consciously and unconsciously, as a distinct experience as well as part of a larger experience. It's presence was felt by families in terms of it's objective costs as well as its experiential subjective manifestations (Falloon 1986).

As with other important variables in this investigation, a specific question was composed to insure the addressing of this issue during the interview. The specific question reads...<u>Do you feel any particular stigma or burden in having a child who suffered or continues to suffer from schizophrenia?</u>

Twenty out of thirty respondents indicated they felt clear, direct and considerable levels of burden by having a family member, in most cases a child who suffered from schizophrenia.

Even though this is not an overwhelming majority, it is significant in terms of the parents' willingness to openly and unabashedly admit to something that might reflect negatively on them[30].

The twenty respondents were also significant in terms of illustrating through numbers the variety, range and depth of families' and parents' experience with this variable. The experience of the respondents ranged from horrible and frightening events to petty and subtle annoyances.

One mother who is married to a frail, elderly, and sickly man

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[30]. That their openness may not have reflected their feelings about saying they felt burdened. There are probably numerous confounding variables involved here. However that is of little consequence to this investigation. The fact that they spoke about it with such ease is significant in and of it self, considering it's implications in our society.

several years her senior, gives a vivid example of what burden can be like for someone in her situation.

She says of her schizophrenic son who has not responded positively to treatment:

> He used to become loud and I felt embarrassed. I was fighting the situation because I couldn't tell my husband about (Patient's name) mental illness. I never told him. I would hide what was happening at home because my husband worked. At one point 15 years ago (patient's name) tried to strangle me. He cut my wrist and arm and he took the blood and started to put my blood in his face and told me that the way he wanted to see me dead. I didn't want my husband to go to work with that sort of worry.[31]

This statement suggests issues that extend beyond family burden, and even though this kind of violence is <u>not</u> typical of most schizophrenic patients, reflects the extreme experience that parents of schizophrenics may have.

At another area in the spectrum and range of responses to this issue, I found a quite different set of issues from another respondent. This parent is a 79-year-old widow who has been a widow approximately 14 years. She suffers from a serious heart problem and has been the primary care giver of a 38-year-old man with a history of alcoholism, self-mutilating behavior, frequent hospitalizations and chronic suicidal ideation.

Her response to the question was:

> Burden? yes, and sometimes I want to be by myself. But Fred is always there.

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[31]. It should be pointed out that this mother was illiterate and a product backward hills of Puerto Rico. She was also in and abusive marriage. She lived under the threat of being abandoned. She also felt "love" for her abusive husband.

This mother also raises issues other than burden. However, the important elements in her response is the notion that despite the persistent demands of her son's chronic illness, she is being affected by life cycle issues. She is in the final stage of her life both in terms of the family life cycle as well as her own personal developmental stage. Erikson's Integrity Vs. Despair is very much the issue here. She is essentially telling us that her son's illness is denying her sufficient time to conduct her own life review. The latter process is necessary in order to maintain her integrity by looking at her life, seeing where she has been, what she has accomplished, and how she has survived despite her hardships. This is essential if she is to avoid despair as her body fails her.

At the other end of the continuum, to the far extreme, is a mother who makes this statement:

> Oh Burden? Well yes maybe I should say yes. Burden in a way that when the time comes that I'd like to go on a vacation I don't because I worry about him.

This mother is the youngest in the sample as is her son. He has been a behavioral problem for several years but was not been diagnosed as having a chronic condition until recently. His drug use was previously defined as the primary problem. This mother has not yet been "struck" with the realities of the situation the way the two previous mother have been. However, she also reports feeling burdened by the behavior of her son who is schizophrenic as opposed to a drug user. She is also a single parent.

Burden is clearly a major issue for families with a schizophrenic member. It is also clear that the burden, regardless of its type, does not go away. The individual, parents and family must adapt to the situation; they have little choice. How they adapt and how thorough the adaptation is a significant issue.

ADAPTABILITY:

Schizophrenia is a chronic condition which is believed to be degenerative. As previously mentioned, it is clear that stress caused by a number of things, including the burden previously mentioned, is a major component of the phenomenon both as a cause and a consequence. It is clear that an excessive amount of stress can exacerbate symptoms in the schizophrenic. It is also clear that the experience of stress is completely subjective, which means that the definition of *excessive amounts of stress* is idiosyncratic.

Because stress is a necessary part of normal life and schizophrenia is a life-long illness, the patient and the family will be at risk for decompensation and dysfunction on a permanent basis. The family is at risk not only from the stresses of schizophrenia, but from the normal stresses and changes in their lives.

The family and the individual cannot get away from stress, because stress may be generated from within as well as from the environment in which the person is interacting. It is important to try to deal productively with it and minimize its negative effects. Several of the predictable stressors of a person's life such as marriage, child bearing require a significant amount of flexibility. Flexibility is also required as the family goes about launching the child into various levels of society at various times in its development. Adjusting to adult relationship changes, physical changes through maturation and economic changes etc., require a flexibility and ability to change, in other words, adaptation.

For the purpose of this study and in the field of family therapy, family adaptation is defined as:

> Ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational a and developmental stress (Olson, 1986).

The onset of schizophrenia, as with most major illnesses, is extremely stressful. For example, one anecdote drawn from interviews describes a twenty-year-old schizophrenic male who begins to withdraw and complain about the video tape recording that people on the block have of him performing strange heterosexual and homosexual acts. When he feels they are distributing it in bars throughout the city, one begins to take notice. When he becomes agitated and threatens to retrieve that tape no matter what the costs, one pays greater attention. When he fails to sleep for two or three nights because he is worried about the tape and has begun to threaten violence to get it back, one feels that there is a crisis. When he picks up his baseball bat and begins to leave their home to find the person who has the tape, this becomes an emergency.

Falicove indicates that people often confuse Crisis with an

Emergency. She defines crisis as:

> simply the state of things at a time of impending change, the point at which things could get better or worse but at which things will inevitable change.

On the other hand an emergency:

> is the subjective sense that outside help is needed to protect one from undesirable change...Emergency is an awareness of danger of impending disaster.

During the mid-1960's, Kaplan, Langsley, Pittman, Machotka, Flomenhaft, and DeYoung on the Denver project, studied crises that led to psychiatric hospitalizations. Through the study of 200 patients they defined four general types of crises. One type, "the bolt from the blue" is the type of crisis:

> in which the precipitating stress is real, unique, overt, and unexpectable, and arises from forces outside the individual and the family system.

The other three were "developmental crises" in which:

> A relatively normal and expectable change in any stage of development requires changes that are uncomfortable for the family; 'structural crises', in which the family's structure is inherently crisis prone and produces recurrent exacerbations of conflict and caretaking crisis, in which the family becomes dependent on outside helpers who have the power to offhandedly disrupt the family.

Schizophrenia has the potential to expose the family to both types of crises. The family can experience "the bolt from the blue" type of crises several times during the early periods of the illness depending on the nature of the onset. As a case in point, one parent reported how his son became symptomatic in response to his sister being shot, giving an account of "the bolt from the blue". He says:

> well she was a good girl you know, bright and every

> thing. She was minding her business when these two dope dealers got into an argument. There's allot of that round there you know. Worse now. They started to shoot and my daughter got shot, just like that.

Falicov's definition of a crisis should be extended to include events from within the individual or family. These are events which for the average person are so strange, unexpected, and initially incomprehensible that their effects are virtually the same as if they came from outside the parties involved.

Another parent places the onset of her daughter's illness as beginning after the patient herself was shot:

> Oh let me see now, it was about the time she got here.. she came here from North Carolina, near Rocky Mount, you know it? .... Well she came here when she was about.... I'd say five years ago after that she got shot, ok it happened when she got shot. I thought I would die. I wondered, what had I done in bringing her here.

Another mother gives an account of the second psychotic episode her son had:

> Well after we took him to a private psychiatrist in Staten Island, we thought everything was going to be all right. We didn't know he had this, they just told us he was having trouble separating from us and we needed to let go. " G" just became more and more withdrawn then he started to carry on, so we took him the Kings County one night and he ended up at South Beach. It was a shock to us we were confused.

All of these events were experienced by the individuals involved as crises. They felt unprepared and confused about these symptom, exacerbations and presentations.

These crises evolve into emergencies simply because of the progressive nature of the condition and the individual, familial and systemic/societal dynamics involved. To adequately adapt to events such as these, a family and caretaker need resources to be flexible. Adaptation probably cannot occur without flexibility on some level.

It is abundantly clear that these variables are major components of the phenomenon being examined. Once they are recognized and understood in the context of schizophrenia, it is easy to begin to appreciate the experiences of these parents.

CHAPTER SUMMARY

This chapter highlighted four variables which are closely involved in family responses to schizophrenia. They also appeared in the data with greater regularity than many potentially significant other important variables. They were clearly interelated in that the presence or excess of one effected the other. The manner in which the parents experienced the onset of the illness was also influenced by these variables in many cases. An appreciation of the role these variables play is necessary to fully understand or appreciate the process of negotiating life cycle tasks with a schizophrenic child.

CHAPTER IV

STAGE IV: THE FAMILY WITH ADOLESCENTS

(Increasing Flexibility of Family Boundaries
To Include Children's Independence)

INTRODUCTION

The central theme of this chapter is the onset of the illness and the parents' responses to it. Unfortunately, in the sample there were only two parents in this particular life cycle phase. The limited number of respondents in this stage of the life cycle did not reflect the variation in responses among parents in this situation. In fact the range of possible responses as both parents were at the opposite ends of the spectrum in many demographics, experiential and response areas.

EARLY ONSET:

According to DSM-III-R the age of onset for schizophrenia begins in adolescence and extends into the middle of the third decade of the human life span. Cooper (1978) writes that the disorder tends to start quite early (age 18 to 35), often before the individual reaches sufficient maturity to leave home, marry or live independently.

In Western culture the age of eighteen is often thought of as the quintessential age of adolescence in the life cycle. It is situated between early adolescence when child-like features are often still physically present, and young adulthood with its early stages of maturity, vitality and impatience.

Adolescence is a period within the individual's life cycle when rapid physical, cognitive, social and sexual growth which started in puberty, blossoms. It is a time when young people begins to "feel their oats". In so doing, they solidify their own identity and attempt to become autonomous in a manner different from other phases of the ongoing separation-individuation (Mahler 1979) process. To successfully manage these tasks, they must deal with a variety of forces from within, as well as the outside environment. They must regulate the social pressures exerted on them from several sources. This modulation must be done in order to create the proper conditions if the adolescent is to continue healthy autonomous development.

Adolescence is also an important time in the life cycle of the parents and family as a unit. The burgeoning sexuality of the adolescent, among other things, can stimulate a number of personal issues for the parents as they enter mid-life. Both parents may once again begin to pay attention to issues that were placed on the back burner during their primary and very busy child rearing years. They may begin to reevaluate their life choices in terms of their marriage and careers (Rosenberg, 1981; Gould, 1972; Levison, 1978; Neugarten, 1986; Vaillant, 1977).

The questioning of parental life choices and circumstances may be as disruptive to the family unit as the adolescent's questioning and challenge to authority and the status quo. The parents may be looking for direction, purpose, and new meaning to their lives. They may be feeling the burden of their obligations to the individuals and systems they have been a part of for some time.

They may also be burdened if they are called upon to become the caretakers of their parents, if their parents health and economic factors demand it. These issues and many more are commonly referred to as the "mid-life crisis".

Adolescence as a state of being also has relevance to older generations. Grandparents may be facing retirement which is a major life cycle event for them as individuals and as a couple. Some of their concerns may be financial. They have already passed their peak earning years and may be anticipating or may have already begun to manage on a fixed income.

There are health concerns as well. Parents are becoming or already have become physically less capable of performing many activities they were capable of before. They are more vulnerable to aggressive and unfriendly forces; be it a mugger who could easily take advantage of them, gravity, disease, time, aggression from and agitated offspring who is an aggressive schizophrenic.

Cognitive changes may become noticeable whether the parent is completely healthy or not. They begin to notice differences in their thinking as compared to twenty years ago or compared to younger adults. They may notice that they are less quick and sharp but more comprehensive in their cognitive activities. These changes and experiences are not necessarily a consequence of the aging process but they become more noticeable at this time.

They now benefit from a lifetime of experience and accumulated wisdom. Their interest in the specifics and the technical may not be what it once was, while their appreciation of the context may have broadened. Socially they are faced with an ever shrinking social network and possible social supports as well. The eventual demise of their mate may also be a concern. Generally this is a torrid and tumultuous time for the family. Consequently, it can be a time of heightened emotional stress. To survive, the family unit must tackle a variety of issues on a variety of levels while maintaining its structural integrity and responsibility to nurture and support all of its members.

The task of the adolescent in the family, whether they accept it or not, whether they are cognizant of their power or not, or whether they consciously rebel or conform to every value and the prescribed behavior of their parents, is to function as a catalyst for change within the family unit at that stage of the family's life cycle. Ideally they will take the family to a new place which is more suitable to the inevitable changes taking place within themselves and around them.

The roles through which these tasks may be accomplished include the role of the rebel, the instigator, and the exposer of faults and weaknesses within the family system that senior members can no longer see or respond to on their own. This role seems to be the permanent domain of adolescents within the family life cycle in our culture. Their presence in the family seems to challenge every family convention, whether through direct or indirect means, consciously or unconsciously. These roles are not necessarily played out in disruptive ways. Many adolescents are quiet and conformist. However their personality does not negate the changes that must occur within a family when certain developmental changes take place. For example, the beginning of menstruation of a female adolescent raises issues of responsibility, sexuality, mortality for both parents.

While the adolescent is attempting to adapt to new power in the world and to find a comfortable place for him/her self, the family must also adapt to the adolescent's new transformation. Nydia Garcia Preto (from Carter & McGoldrick's 1989) writes about the transformation of the family during the adolescence years on one of its children:

> The adaptation in the family structure and organization requires to handle the tasks of adolescence are so basic that the family itself is transformed from a unit that protects and nurtures young children to one that is a preparation center for the adolescent's entrance into the world of adult responsibilities and commitments. This family metamorphosis involves profound shifts in relationship patterns across the generations, and while it may be signaled initially by the adolescent's physical maturity, it often parallels and coincides with changes in parents as they enter mid-life and with major transformations faced by grandparents in old age.

Adolescence is a time when the family and the authorities within that family have many options available to deal with the stressors of the stage. It is difficult to know what the right decision is and to what extent the decisions reached should be applied to a particular situation or an individual adolescent. For example, the issue of curfews. When should they be imposed, till what time, under what circumstances, what happens when they are violated and when do they not apply or are appropriate any more? How does the parent demonstrate trust in the adolescent and how does the parent give the adolescent an opportunity to demonstrate that they are trustworthy.

Even though the family has to adapt to this new state on several levels at the same time, they must adapt without disintegration or constructing a rigid set of boundaries which inhibit growth and healthy change. As previously mentioned, in order to accomplish this task, the family and the individuals within must demonstrate flexibility. Flexibility will allow the transformation within the system to occur without the disintegration of the system. The groundwork for these changes should be laid down by the parents during the earlier stages of the child's life and development. Transition is generally not smooth because in many ways the adolescent is a new and different person. The installation of early experiences such as trust, discipline, self respect etc. seem to smother transition.

Without flexibility none of the second-order changes, necessary for the family system's survival, will occur. The individual family member and the adolescent will not feel able to move out of the system and establish an orbit from which they can safely experiment with new social entities, constellations and states of being. They will not be allowed to augment the system by bringing in new people even on a temporary basis regardless of the benefits. Nor would the family be able to recognize the changes, and new powers and traits of the three generations that are likely to interact with one another within the family system.

The presence of a chronic illness which is not well understood, adds additional pressures to the situation. There is a basic contradiction in what is required of a family in this situation. The family is required to be flexible, take risks, tolerate and adjust to losses, tackle threatening and frightening issues, resist the destructive tendency to try and maintain the status quo.

At the same time with the onset of schizophrenia, it is faced with a situation of unknown and frightening proportions. The normal reactions to such crises at least initially is to *DEFEND* the structural integrity of the unit by firming up the boundaries, or become defensive. Webster defines defend as "To forbid to prohibit" Britannica defines it as "To shield from attack or injury; to protect". Defending the person who is afflicted or attacked, as well as the integrity of the system against threatening conditions is natural and primary to the survival of the family.

A defensive position is a position which is closed, rigid and impervious to outside influences. Hence, two powerful yet opposite forces are being activated and experienced by the family, the parents and the patient at the same time. The structures and boundaries of the family are being bombarded from both sides while being required to transform, and the patient is being bombarded with extreme social and behavioral stimulation while being internally stimulated in a new and confusing manner (Hallucinations).

During onset, the symptoms and characteristics of schizophrenia are many and confusing. DSM-III-R (Diagnostic and

Statistical Manual, Revised) lists of characteristics are:

> social withdrawal, impairment in role functioning, peculiar behavior, neglect of personal hygiene and grooming, blunted or inappropriate affect, disturbance in communication,bizarre communication, unusual perceptual experiences, and lack of initiative, interest or energy.

Unfortunately many of these behaviors by themselves, or even in minor combination, would not be drastically different from behavior expected in many normal adolescents during this tumultuous life cycle phase. As a result many patients and families are not fully aware that their child is becoming symptomatic, and this is especially true for the initial onset symptoms. This problem is further complicated when the patient has a number of crises within a short period of time. The complications continue with the long recovery period which follows[32].

Because of this protracted period of recovery, many parents may react by generating and maintaining a high level of anxiety within the family. Alternatively they may underestimate the significance of the situation by not protecting the patient from the stressors which may lead to another psychotic episode.

Paradoxically, parental reactions often create an environment which may exacerbate major symptoms. One parent illustrates what both she and her son went through during the first post-hospitalization period. She also illustrates the difficulty in differentiating normal adolescent behavior with prodromal symptoms. She says:

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[32]. It is estimated that the time necessary to recover from a major psychotic episode can range any where from eighteen months to two years. (McFarlane, 1984)

> I'm always like very watchful which he resents because he says why are you always staring at me. But it seems that I unconsciously watch for any signs if any thing is going on and I don't even realize that I am doing it.

Another parent expresses less active vigilance:

> My major concern as a parent for Navada is for me to get him back as normal as he can get, and see where he's going.

Parents or caretakers in this situation seem unsure about the behavior they are seeing when they look at their loved one. The anxiety and subsequent diligence about seeing the patient's early symptoms tend to be expressed in a manner which can seriously interfere with the developmental tasks and normal role changes at hand.

One of the tasks for the individual as well as the family vis-A-Vis the individual during adolescence is:

> To establish autonomy they need to become gradually more responsible for their own decision making and yet feel the security of parental guidance (Carter & McGoldrick's 1989).

In dealing with the illness the family can postpone all developmental tasks and hold itself and the adolescent in a frozen state of pre-adolescence. Or it can dissolve from the multi directional forces to which it is exposed. More productively, the family can muddle through each crisis and emergency with the use of its own available resources.

To get at the thoughts and feelings of the parents around the issue of <u>Shifting of Parent Child Relationship To Permit Adolescent to Move In And Out Of System</u>, and other stage IV issues, several questions specific to this change were asked.

The issue of "the shift" seemed to be present across all three developmental stages. As the subjects became chronologically older and moved from one developmental stage to the next, the issue became more blurred and less obvious, but they were present and influential never-the-less.

The issue of "shift" was clear and strong among the two parents in Stage IV. One mother passionately describes her situation and struggle to do the right thing by her son in terms of his development. She is also a single mother who is shaken by the loss of her husband to his greater love, alcohol. She speaks of her son who as yet has no telltale signs of chronic schizophrenia because on medication he seems so normal. However, he clearly presents a clinical picture of a schizophrenic.

> I would ah.. I would like to see more independence as far as you know (him) taking up responsibilities around the house because I find that he seems to be extremely..... very self centered since he was in the hospital and you know he is only involved in what he wants to do. We ask him to do a chore he just wont do it. You know like if we are cleaning or something and I ask him to clean the table because he has a habit of coming in and putting every thing that he owns on the table and that irritates me you know that he makes a mess as old as he is and when you ask him to do it he'll tell you I'll do it and he just will not do it.

This mother seems to be struggling with a number of relevant issues at the same time. She wants the patient's cooperation in domestic matters especially because she is a single mother. She is annoyed when he declines to participate in taking care of their home, or when he does the tasks perfunctorily in his own time. She is also aware of the appropriateness of allowing choice, promoting responsibility and not participating in perpetuation maladaptive behavior by compensating for the person's self imposed deficits or limitations, as when she was a facilitator to her husband's alcoholism. Despite this awareness, she still struggles to understand what schizophrenia requires of the caregiver.

In response to the question concerning her rating from 1 to 10 with regard to how independent she feels her son is at this point in his life, she continues with her complaints:

> I would say a six because he is very independent about something that concerns himself. But even getting up and going to school I have to wake him up or call him to make sure he that he is up. And now as I said if it's any thing that concerns his music or if it's a show now you wouldn't have to get involved at all he'll be up and ready and be able to get out.

It is very confusing and frustrating for a parent for whom these issues are developmentally appropriate and who's expectations were tempered by the unexpected and poorly understood changes taking place in her child. She must now demonstrate flexibility, tolerance and a willingness to not force her agenda on her child while at the same time setting limits and requiring optimal productivity from him.

> Oh well I expected him to grow up into you know, he always said he was interested in medicine and that was his first choice. And then after now he said he was going into music which (the therapist and the psychiatrist) feel well I'm a bit too ambitious I should leave him alone and not try to steer him back into that course.

For some parents the amount of support and education they receive seems to go a long way toward helping them develop a sense of control and competence in dealing with the onset of the illness. This seem to help when moving on to their next set of tasks which is the Shifting of Parent Child Relationship To Permit Adolescent To Move In And Out Of System.

Among the parents who are in Stage IV of the life cycle, there was a clash between what they expected of their children and what they were now getting in terms of behavior and performance. There was sadness as they observed their children. They seemed disappointed not only for their sons but for themselves as well[33].

Even though only one of the two parents admits to feeling burdened, both complained of various burdensome problems the condition had visited upon them. One parent talked about the problem of her son's non-compliance with treatment and the problems it presented to everyone with whom he came in contact:

> I have a difficult time trying to get him in because it's always a situation where I have to deceive him to get him in you know, so it's quite hard by the time he seeks the help you know, that he gets it he's really bad off.

Both of the parents who are currently in Stage IV are single parents. In addition, both have younger children who also require their attention. One has several younger children. The responsibility that a schizophrenic child adds to this stage of parenthood inevitably increases their sense of burden.

In responding to the stressors and burdens of this illness, parents of schizophrenic children must have particular resources and skills available to them for problem-solving. The F-COPES instrument was used to measure five general categories of problem solving methods and support among the subjects. The five

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[33]. This issue of the parents own aspirations for themselves and their children will be dealt with later on in this chapter.

categories are *Social Support, Reframing, Spiritual Support, Mobilizing The Family To Get Support, and Passive Appraisal* (See Methodology Section or list of terms For Description of terms).

The two parents in Stage IV varied considerably in their use of or access to social supports. One parent seemed to agree that she and her family utilized social supports when faced with problems in the family. She called on friends, relatives acquaintances, professionals, whomever she believed could help her.

The other parent responded with indifference to the use of social supports when faced with a problem in the family. Her indifference to the use of social supports may be a reflection of her lack of knowledge and competence in accessing and activating the help of her neighbors, friends, social service agencies. It may also reflect a maladaptive personality trait. She presented as a very passive almost socially incompetent person despite appearing to be intelligent.

There were also significant difference between the parents of this stage in their use of spiritual support. Parent #27 who utilized social support regularly rejected spiritual support. She claimed to have a strong faith in God, but strongly rejected all other aspects of organized religion such as church activities and charities. She never attended church, never participated in church activities, and never sought advice from the clergy.

On the other hand, parent #22 who seemed incompetent in the use of social support was neither accepting nor rejecting of spiritual support. She had a strong faith in God but strongly rejected seeking advice from a minister. She did attended church occasionally. This passive use of spiritual resources is consistent with her limited use of the social supports available to her.

As table #3 reflects, both parents scored low in mobilizing family support. It was very clear from their verbal accounts that they felt isolated and unsupported by family. The parent who scored the lowest in this area was parent #27. Her response to question number 26, Have you had any concerns about the welfare of your son/daughter when you are no longer able to care for them as you presently do?, illustrate her feelings about social and family support.

> Yes I would worry about that because you know the father he's certainly couldn't turn to him for any help because he hasn't been any help at all.

Neither parent embraced passive appraisal as a method of solving problems facing the family; in fact they rejected it. The parent who most strongly rejected passive appraisal, also strongly rejected spiritual support and had the lower score in mobilizing family support but higher in social support.

The tone of her responses and the constellation of her F-COPES scores conjured up an impression of independence, assertiveness, rationalization and intellectualization in handling problems. There seemed to be a strong belief in self reliance. In describing how she gets her son and co-workers to do certain tasks, she demonstrates her emphasis on self-reliance and is impatient and her lack of confidence in others when a job has to be done:

> To me it's less exasperating to just get it done and do it myself.

Where as this might reflect other issues with this mother it is a strength which indicates her tendency to be self-activating and self-reliant.

Nonetheless, this mother consciously struggles with the conflicts of her situation. She is aware of the patient's developmental needs, as well as some of her own. She is also clear about her hopes for her son and herself. And she has developed some awareness of the patients limitation as well as some of her own shortcomings in dealing with the situation, she says:

> I don't want an argument with him or cause any stress.

This mother has been educated about the vulnerability to stress of schizophrenia and the need to be flexible:

> I would say I'm flexible in some areas and then I'm very rigid in others.

On the other hand, the other parent, (parent #22) in this stage seems more disorganized, less cognizant of certain developmental issues, has fewer social supports and is less likely to use the social supports, she leans more toward spirituality and is more passive.

Her son's general functioning has already begun to deteriorate faster than the other patient in this category. He has already had many more hospitalizations, has had contact with more social service agencies, is more resistant to treatment and is less clear about his goals. He is also unrealistic in the goals he is currently aspiring to. This mother has not received information about her son's illness and how she can manage certain aspects of it.

As a group, the parents in Stage IV seem to employ reframing as a method of problem-solving quite regularly. This involves viewing problems in a more positive light so as not to get discouraged. This positive approach appears to be very important in managing the issues of their situation[34].

F-COPES Scores of Parents in Stage IV

Table # 3

# OF CASES	SOCIAL SUPPORT	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL.
Case # 22	18	30	12	11	8
Case # 27	28	33	8	7	4
Central Scores	27	24	12	12	9

Central Scores= Neither strongly agree nor disagree

Both mothers espouse positive attitudes in looking at their problems. However, despite their relatively high reframing scores, their normative statements are not as convincing.

Both parents were asked follow-up questions to question number 23, Have you ever thought of when your basic parenting responsibilities will end? The mother of patient #22 responded by saying:

> I'm beginning to have doubts. I no longer feel that hopeful for Navada. For the other kids I have more faith.

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[34]. They may aspire to it but they don't necessarily practice it. The transcripts is sometime inconsistent with their claim.

This pessimism is present throughout the interview. There is a discernable gap between her ideal, the attitude she apparently aspires to, and what she feels more deeply, which is pessimistic and sad.

On the other hand, patient number 27, Sidney, not only aspires to having a positive attitude, but seems to have achieved it in many ways. She is aware of specific ways in which she can set limits and the importance of limit-setting in getting things done. She also understands how limits tend to generate a sense of security and confidence.

She reframes things in a manner which allows her to deal with problems more systematically. She appears to be interested in learning new methods of problem-resolution. And she does not rely on cliches or empty popular phrases to guide her.

Unfortunately, this fourth stage only had two subjects from when data could be gathered. However, based upon practice experience I believe they are reasonably representative of families within this stage of development. When these parents and their responses are compared to the rest of the sample, the following is observed.

Half of the patients in the study experienced their first and second psychotic breaks during their adolescence. These were designated as early onset cases.[35]

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[35] Early onset was significant because many of the patients in the subsequent stages would have gone through adolescenc while dealing with this problem. It seems reasonable to compare the early onset patients who are currently in stage V and VI with the patients and parents who are currently in stage IV.

Early onset patients appear to be different in many ways from those whose onset occurred in early adulthood or later on in life. As a group the level of functioning of early onset patients was lower and their prognosis was more limited. In addition the severity of these symptoms was greater. Generally they appeared to be sicker as a group than the patients whose onset occurred later in the life cycle (See table # 2).

The family members of early onset patients were also more prone to disorganization, high stress, and "burn out" than parents of those who became symptomatic later on in early adulthood.

Number of Patients and Level of Functioning Among Early Onset/Late Onset Patients

Table # 4

AGE OF ONSET	#OF PTD	LEVEL OF FUNC.	#OF HOSPTL	FB	NO FB
Adolescence	16	5.2	5.3	11	3
Adult	15	4.8	2.4	6	6

DSM-III Scale: 1=Superior functioning, 7=Grossly impaired

Using DSM-III criteria for rating patient's functions one can compare the functioning between the patients in stage V and stage VI. Among patients whose onset took place during adolescence, but whose families are currently in stage V or VI, all but one are currently functioning at a level above good (3 or less)[36]. These patients and their families seem to be struggling with the same issues with which the patients in stage #4 are currently dealing. These issues include denial, family burden, various level of problem solving ability based on access to supports. Here is a brief description of a few of those early onset patients and their families. This description is of the patients and families after they have struggled with the issue in stage IV.

> Among the patients in this group, patient # 6 is probably the highest functioning of all. He is rated as the highest functioning because he has steadily progressed through the mental health system the way one would like to see progress. He has benefitted from treatment despite a mental health system which generally lacks fluidity and continuity of services. However, this patient's success can be attributed to a number of factors, one of them being the flexibility and continuity of services a facility like S.B.P.C. with its ability to enable the practitioners to collaborate with a variety of agencies to maximize his potential.
>
> This patient slowly progressed from a mute, almost catatonic person who attended clinic and day hospital for the first few years of his illness. He eventually moved on to varying levels of day program including a vocational training program during a fairly early stage in his treatment and recovery. He then moved out of his parents' home into a supportive residence where he developed specific skills of independent living. He then moved on to a higher level of indepndent living which supported his social management skills.
>
> After experiencing success through these various services, he went through a vocational evaluation process which led to his enrollment in a cosmetology program at a well know New York training institute. He struggled to

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[36]. DSM-III rates level of functioning from 1 to 7. On this scale ONE represents SUPERIOR functioning which is "Unusually effective functioning in social relations, occupational functioning, and use of leisure time". SEVEN represents GROSSLY IMPAIRED which is "Gross impairment in virtually all areas of functioning". See entire scale in the tables and charts section.

overcome the emotional hurdles of the training program, which were related to fellow students who were unaware of his disability and who found his style of dress fascinating and sometimes laughable. The patient dresses in a manner similar to many futuristic science fiction characters.

He eventually graduated and proceeded to find competitive employment in the job market. The demand of eight to twelve hour work days proved much too stressful for him, and he eventually withdrew from that particular type of work. Nonetheless, before the patient left this line of work he tried employment at various cosmetic shops to see if he could adjust to the rigors of full time employment. Unfortunately, the customers demands for perfection when it comes to their hair styling and the speed which is required by employers, was beyond his tolerance. Despite these pressures, when he did work he performed competently and met the demands of the employer. He was never fired and on several occasions when he left, he was asked to reconsider.

His employer and co-workers were not aware of how symptomatic he would become after leaving work. They also were unaware that he became delusional and hallucinated at work on a few occasions but was able to utilize the "borrowed ego" of his therapist and psychiatrist to guide him through the experience by saying to myself, now what would Dr. A and therapist S say I should do.

He was fortunate in that his symptoms were sufficiently ego dystonic so that he was able to exercise some control over his behavior during psychotic state. After discontinuing his full time 40 hr. per week job, he continued to experience a minor exacerbation of symptoms. Even though many possible stressors of employment were thoroughly discussed for several months, the preparation did not include the unknown. The patient had agreed to work only 6 to 8 hours per day when he interviewed for the first job. Once he started to work, he was asked to do what was required to help take care of the customers. This included working longer hours on a daily basis and his new found desire to please the employer out of gratitude. He eventually returned to his parents' residence under a new set of agreements with them, and he ended a relationship with a young woman whose instability and demanding nature was stressful for him. Even though it took approximately six to nine months for him to fully recover from that two-month episode, he received and eventually accepted a part time job in a senior citizens' organization doing a variety of tasks. At this agency he performed well at many tasks which keep him busy but not over-stressed. At present, the patient has made several positive changes in his life and is savoring these accomplishments. Both of his parents are still alive and they remain happily married. They are stable and have always provided the patient with a clear point of reference as he has moved through his life.

His mother is extremely religious,well educated and strongly believes in maintaining a positive perspective on life, primarily through her belief in God. His father is relatively uninvolved in the emotional and interpersonal aspects of the family life. However, he feels his responsibility is to be a provider and staunch guardian of his family.

Throughout the course of his illness there were constants which may have contributed to his recovery. The most obvious was the continuity of care the patient received. He had the same therapist with whom he has meet with every week for the past 11 years. He has had the same psychiatrist for the same period of time. This psychiatrist has medicated him and kept him stable. Both the patient and his mother were thoroughly educated by the team about the illness and what to expect because of it. There was open and frequent communication between patients "home clinic" and the other services he became involved with. His current employer is aware of his disability and has been given permission by the patient to speak with the clinical team if necessary. This has provided both the patient and the employer with a sense of support which has prevented many problems.

Another patient presents a slightly different pictures. Patient #19 became symptomatic during high school. The onset of his illness also coincided with turmoil in his mother's relationship with the man who is now her husband. Even now, the patient remains confused about his role in the family and his relationship with his mother. Prior to his decompensation he functioned as a "normal" young man who was expected to realize his potential.

When he became symptomatic, he was incorporated into the mental health system without much resistance either from him or his family. He attended the BSS Day Hospital for a brief period before attempting to demonstrate his autonomy from his family by getting a job, for which he was woefully illequipped psychologically, socially and vocationally.

His failure to find employment increased the frequency of his psychotic episodes, which in turn created additional stress for his family.

Though well meaning, the patient's mother had difficulty recognizing his psychiatric needs. This was especially true when they interfered with her own needs. She often treated him as though he were normal and not suffering from a major mental illness. As a result, she continued to see his aberrant behavior as willful and antagonistic.

At the same time, the patient was dealing with his own chronic mental illness, he had the additional stress of a stepfather who was a compulsive gambler. Needless to say, the combination of stressors did not help the recovery process.

Patient's parents have had some education about the illness and they acquired coping skills which helped in the management of the condition. However, the family has not changed many of its perceptions and they continue to struggle to overcome this. Although they are making progress the patient continues to be very symptomatic and dysfunctional. This family's F-COPES scores revealed a number of important issues.

F-COPES Scores For Case # 19

Table # 5

	SOCIAL SUPPORT	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRAL.
Case # 19	19	32	12	13	7
Central Score	27	24	12	12	9

This early-onset family is low in the use of social support as a method of solving family problems. They employ reframing, and family support is available but only moderately utilized. There is not a clear reading on spiritual support. The lack of clarity is a result of a neutral score on the F-COPES instrument in regard to spiritual support and the patient's mother indicating that she has a strong belief in god[37]. Although this family identifies as Catholic, they do not avail themselves of the support of the clergy. They are low on passive appraisal and believe, among other things that luck plays a big part in what happens to people. This is why they do not completely reject ideas such as waiting around for things to take care of themselves. It has also been pointed out that the emphasis on luck seems natural for a compulsive gambler such as the father figure.

Unfortunately, when they do assert themselves they tend to do so in a less than productive manner. Their assertions tend to exacerbate the patient's symptoms which can set off a chain of negative reactions.

The final comparison is of a patient who had some of the same qualities as the previously illustrated cases. This patient had an intact family, suffered an early onset, and gradually deteriorated over time.

> This patient became symptomatic while attending a large and prominent university. He resisted treatment for two years while pursuing answers to questions generated by his delusions as well as denying the presence of his illness. He entered treatment after a third brief hospitalization. He was subsequently admitted to the day hospital of a major local facility.
>
> He was then transferred to the Baltic Street Clinics Day Treatment program where he stayed for approximately

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[37]. A neutral score on the F-COPES is a score for a particular type of problem solving mechanism that is the same as the central score which is the average score one would get if they were to answer "neither strongly agree or disagree" to all the problem solving methods of that category.

nine months. He remained symptomatic throughout his stay in the program. He was non-compliant with medication and found following non-medical aspects of his treatment plan bearable.

He eventually withdrew from day hospital treatment and was treated exclusively on an outpatient basis. To be successful this form of treatment requires a certain level of stability and acceptance of one's condition. It does not offer the level of support and supervision that the day hospital offers. The patient is exposed to normal stressors without the buffers of medication, and social milieu support.

Ultimately the patient's parents were invited to participate in the therapeutic process which they accepted. Unfortunately, the patient's father remained alcoholic and patient's mother struggled with holding her family together and protecting herself from her threatening son. Unfortunately, these parents were unable to provide the support or set limits both of which he desperately needed if he was to gain some control over his symptoms. They seemed stressed by both the patient's antics and threats as well as their own unresolved marital conflicts, most of which revolved around the patient's father's drinking.

This patient has not been able to conform to any of the most basic rules of society. Since becoming symptomatic he has had to be forcibly removed from his parents' home by the police on several occasions. He has assaulted and attempted to rape his mother. He is generally in conflict with just about every member of the treatment team at the Baltic street clinic. And he frequently gets into fights with people in the community. He has lived in a variety of places, none for any considerable period of time except for the men's shelter where he has been for well over one year. Prior to that he was shuffled from shelter to shelter because of disruptive behavior.

Recently the patient was imprisoned in Rikers Island for assault. He has continued to deteriorate in just about every aspect of his life. He seems stuck in the time of his first psychotic episode, and continues to talk about the events he believes led up to his first break. His parents continue to register the same complaints about him today as they did during his recovery from his first psychotic break.

Despite numerous attempts to help the patient's family deal with management problems, they seem unable to

> alter their own behavior, either through an effort to shape new responses or through new understanding about the patient's illness.

Turmoil, confusion, lack of stability, lack of limits, and unrealistic expectations as well as biological and psychological processes all contribute to this patient's continued symptom exacerbation and poor level of functioning.

The developmental issues become less obvious but nevertheless just as pressing and problematic as these patients and their families progress through the life cycle. It seems the turmoil created by the onset of the illness during adolescence arrests certain aspects of the development of the family's life cycle.

Schizophrenia is a chronic and degenerative illness with frequent exacerbation of symptoms, frequent crises, and frequent emergencies. *The cumulative stress on the family becomes a major survival issue. Because of these stressors and the lack of rebound time required by all people following an encounter with extreme stress, the family has little chance of recovering from psychotic episode and resuming the developmental process. Hence early onset patients and their families continue to look more regressed and dysfunctional than late onset patients and families.*

Problem-solving among this early onset group reflects their general state of mind, their use of available resources and their perception of the tasks ahead of them. They seemed less patient less appreciative of the process which requires patience and letting things happen when required. A metaphor for this phenomenon would be to describe these parents as not wanting to wait for the slow heat baking of a souffle. Instead they wants to turn the heat up as high as possible and get it done as quickly as possible.

As a result of their impatience they and more willing to take thing into their own hands. When one of the mother in this category was asked How do you solve problems within the family? replied...She replied:

> Well I'm the family, I make the decisions.

Another mother is less abrupt:

> We all get together and try to solve them together. If not then whoever the problem is then they think they can manage it they do it themselves.

This stage of the life cycle when schizophrenia is present seems to effect all families in much the same way. The manner in which the family reacts to the situation seems to be directly related to the resources both internal and external available. These resources may include education, innate intelligence, financial flexibility etc.

REFOCUSING ON MARITAL AND MID-LIFE ISSUES:

As shifts in the parent-child relationship unfold, they create natural imbalance within the family structure. This imbalance has a rippling effect within the family which impacts on all existing family relationships. As previously mentioned, theoretically, as one constellation changes, the family must be flexible enough to tolerate the repercussions of that change. Thus as adolescents becomes less close to their parents, and in many cases, loudly proclaim their independence and non-connectedness, there is a ripple which disturbs the homeostasis of others, especially the parents.

As one constellation within the system changes, each subsequent constellation must increase or decrease and respond to new demands, discoveries, and needs. New and unpredictable opportunities present themselves to individual members of the family.

The parents and grandparents begin a long and arduous process of reevaluation and assessment of their lives. The parents in particular seem to experience the greatest repercussion.

Neither of the parents in stage IV were married at the time of their interview. One was employed at the time; The other was on public assistance. The latter was also the youngest subject. As mentioned elsewhere, she found difficulty responding to many of the issues raised by the questionnaire simply because she is not there yet, chronologically, psychologically, or socially.

Instead she sees herself as still a relatively young person who is looking forward to the promises of the future. She said little if anything that would indicate she had become fully aware of her own mortality and the benefit of celebrating her concept of time, goals, and expectations.

Most of her responses to questions were in terms of her son and the systems with which she must interact. She indicated that she felt burdened by the illness. However, she felt able to handle the situation and seemed prepared to be involved with it for at least awhile. Going back to question number four which was Did you feel any particular stigma or burden in having a child who suffered and continues to suffer from schizophrenia? Her response was:

> Yes, I feel a burden. Well everybody has different problems that they have to deal with along their way in life. Like mine is just coming up now. So I'm sort of grateful because I can handle it better.

This parent is not responding with the benefit of knowing certain basic facts about the illness. In subsequent discussions it became clear that she believed this situation would be resolved as other medical problems are resolved. She believed the resolution would be through medication which would in time erase the symptom.

Her response to the question, What are some of the major concerns for you as a parent at this time in your life? was understandably not revealing. If it is taken in the context of all of her answers, one gets a better sense of where she is in relation to this issue.

Her response of:

> My major concerns as a parent for Navada is for me to get him back as normal as he can get and to see where he's going yo stand and what steps I can take after that for his future.

...suggests that she has not yet begun appreciating time in a more mature manner. She may have seen her son as eventually growing up but not herself as growing old in any real sense.

Her sense of self-satisfaction is also unfocussed. She reports feeling some gratification around the seventh month of her pregnancy, but she was not sure what may have contributed to that sense of satisfaction. Her response to What affected that sense of satisfaction? her reply was:

> Ah, well I guess some sort of satisfaction because I achieved something.

The final piece of *evidence* that this task may not be a conscious issue for this parent is her response to the two last questions on the questionnaire. Both questions tacitly speak to the eventual death and completion of the parents' life cycle. They are; Have you had any concerns about the welfare of your son/daughter when you are no longer able to care for them as you presently do? and Is there anything you would like to take care of before you reach that point? To these questions her responses were:

> Yeah, I'm starting to give a little thought to that. And because I don't know what's going to, what the outcome will be.

> Well I was talking with a therapist and he said that he [the patient] would probably do better in a half way house. You know as part of the program of bringing him as close to independence as possible.

She is looking forward to her son's recovery and progress without the sense that she will change or not be around for him. She seems to be responding more to the sense of burden at the moment than the sense of mortality which comes with age.

This mother is still struggling with defining herself as an adult and a parent. This ultimate developmental task is simply not a conscious issue for her at this time.

The parent who was employed seem to relate to this issue in terms of her career. She identified herself as a professional woman who had a life separate from her role as a mother. She associated with professional women and intended to continue this practice because she saw them as her true friends. She identified her gynecologist as one of her closest friends.

Her reflections in terms of her role as a parent seem equal at times to her thoughts about her professional life. As mentioned in another part of this paper, she gained insight into a few important areas of her interpersonal relationships and works on improving herself in this area.

In terms of career she made a statement of significance. That statement also sums up her position on other mid-life issues as well:

> Really the only thing that I'm hoping for right now, I'm thinking of maybe taking a graduate course since I found out the job will pay for it. I feel now it's time for me to do things I wanted to do with myself since they(Children) are now able to take care of themselves. Hopefully in the next few years everybody will be out of school. I will say (that is) from the way things have been done in the past. Because I mean all responsibilities has been on my shoulders ever since they were six and eight years old.

Like the other parent in this category, she and her family appear to have been spared some of the behavioral, structural, marital and familial turbulence of the "Middle years". However, what was substantiated is much worse. The demands of schizophrenia are much worse in intensity and unabating stress because of it' duration. If it ever does ease or goes away, it may do so only after several decades (Harding, Brooks, Ashikaga, Strauss, Landerl, 1987). Neither parent commented on the possibility of romantic relationships in the future.

To gain a broader perspective on this issue I included the early onset parents of stage V and VI. The premise was if they are in the subsequent stages and they were early onset cases, they must have had to face similar issues, for chronological or maturational reasons. When this issue was explored for these early onset parents, the refocusing on marital and mid-life issues does not seem to be as prominent an issue among parents in stage IV as it appears to be with other individuals at this stage or those who recently went through this stage. This is not to say that it does not exist or express itself in another way. For example, one parent does express concerns about the quality of her life:

> Well sometimes she is a burden, sometimes you get a little mad about it

When all the early onset parents were examined, this included those in stages IV, V, VI, it seems that their child's illness dominated their consciousness for great periods of time. Those in the last two stages V, VI, all seem grateful for what peace they have at the moment. Other issues such as the benefits of a mate, and self actualization, seem to be recognized as important, but of little relevance to them at this time.

Where there were couples, they were still focussed on the patient but were not and had not been in a crisis state for several months, and in some cases, years. Still, there was a lack of mid-life unrest.

I then decided to break the issue down into the components I believe go into creating the issue of mid-life crisis, and/or its resolution. These components focus on one's own needs, self satisfaction and marital satisfaction.

From clinical observation, most of these families give the impression that they are stable and were not greatly concerned about their own needs. Half of the parents in the early onset subgroup reported a sense of satisfaction with themselves and their marriage. Most of them were in stage V of the life cycle. For the most part those who were not currently married had not thought about these issues. Most of them seemed preoccupied with the management of their child, and there was nothing in their life at the moment that was forcing the issue.

The reasons given for this sense of satisfaction varied. Some of the reasons included personal maturity. One married mother says:

> I feel I'm accomplishing more, I'm doing more things and people are complementing me on the way I'm growing and doing more things.

Having personal wishes fulfilled by God. An extremely religious mother who is also married, gives God the credit for answering her prayers. She says:

> I don't know about when I had the children, well it could be because I always wanted boys and I had two boys. And then I wanted a daughter, I got a daughter. So I would say I feel satisfied because most of the things I wanted I've gotten. They are very good children.

On the pleasures of having young children. One mother simply said she received a great deal of satisfaction:

> When the children were young

A similar response came from another parent:

> I guess maybe the last five years, This is a hard question, I guess when my children were very young I was very satisfied I enjoyed staying home and mothering those were very happy years when the children were very small and then I'd say it was more difficult years when they were teenagers and now I'd say it's more satisfying again now that everybody is more independent.

Another said:

> I would say when I had Sidney...The birth of my first child.

Having a strong family bond was most significant to another parent:

> We are very close. There is a close knit family. My children my grandchildren it's always been a close family.... With myself? Yea when I had all my children to know, when I realized I had four children, I raised them to be the best of my ability and I feel satisfied with myself, my work my home, my wife.

Another father cites the purchase of a house and his role as a provider as a source of personal satisfaction...

> That was... that's easy. That was when I got the mortgage for the house. The mortgage, home. The children were was small you see, it was 1969 so I was 49 and one was born when I was 34 and the other 39. I got something for all of us that was in 1969. I felt I had accomplished something.

A single mother who emigrated to this country from Latvia when she was still a young woman, and is in the last stage of the life cycle:

> Working and feeling independent.... I was not completely satisfied with my marriage that's for sure, but I felt so [satisfied] about when I worked. I felt I can manage every thing. My marriage was one of what kept me all the time down.

With the exception of the one remarried couple, all intact couples with an early onset child seemed to have achieved a stable state in their marriage. They appeared to have resolved many difficult issues, registering a sense of satisfaction with their family and themselves. The satisfaction seemed to be based on personal growth in surviving something and coping with their child's schizophrenia. As one respondent put it:

> ...Right now I'm satisfied with myself I've grown.

Probably not coincidentally, all have other children who are healthy and doing well. Most of these parents cite the success of the healthy children as a major accomplishment and a healing experience for them. It serves as a buffer between the everyday reality of their stricken child's illness and the tendency to self-blame for causing the illness.

As a group their F-COPES scores were low in social supports and passive appraisal. They did a great deal of reframing and strongly agreed that they used spiritual supports when dealing with problems or stresses. They were also able to mobilize family support when necessary. ***A great deal of that support came from the healthy children, a few extended families, but primarily from their mates.***

Comparison of Early Onset Groups/ Couples, Single Parents.

Table # 6

CASES	SOCIAL SUPPORT	REFRAMING	SPIRITUAL FAMILY	MOBILIZE APPRSL	PASSIVE
	N=27	N=24	N=12	N=12	N=9
COUPLES	25.6	30.6	13.1	15.2	8.5
SINGLE	21.4	27.6	8.8	13.6	7.8
AlL EARLY ONSET	23.6	29.7	11.7	14.5	8.2

Most of the parents who are still married reported a sense of satisfaction with themselves and their marriage. The have all been married at least twenty-three years.

The reason given for their sense of satisfaction seems to be personal growth. One mother clearly differentiates herself from her family. She says:

> Right now I got satisfaction with myself. I've grown....I'm accomplishing more.

She then included her family by saying:

> When Dean was born, the way the other kids reacted in this house I loved them.

Most parents identified the birth of their children as time in their lives when they felt the most satisfaction.

The single parents in this early onset group, were not so fortunate. All of their children were moderately to severely symptomatic and repeatedly had difficulty with treatment compliance, boundaries and authority. These parents' F-COPES score indicate they utilized fewer social supports, did a good deal of reframing but not as much as couples, did not utilize spiritual supports, were considerably passive and were able to mobilize family supports less than intact couples.

CHAPTER SUMMARY

The role of onset and the families reaction to the schizophrenic behavior was the central thrust of this section. The first major period of turmoil in the schizophrenic process was explored with data suggesting that the family coping with schizophrenia is in a perpetual state of crisis. Families, nonetheless exhibited two extreme reactions which suggests that there may be a wide range of reactions from the families dependent on their resources both emotional and instrumental, and their flexibility.

CHAPTER V

STAGE V: LAUNCHING OF CHILDREN AND MOVING ON

(Accepting a Multitude of Exits from
and Entries into the Family System)

INTRODUCTION

This chapter will explore the experiences of the parents as they deal with the life cycle issues of the fifth Carter McGoldrick life cycle stages, Launching of Children And Moving On. Their responses to the specific tasks, namely dealing with the centripetal[38] forces created by the stretching of family boundaries. This is especially true if there is another young adult in the family who is capable of moving on. Other issues facing the parents during this phase of life are the renegotiation of their marital system if possible, developing an adult to adult relationship with adult children, realignment of relationships to include in-law and grandchildren and dealing with the disability and eventual death of the parents and grandparents.

As with the other two life cycle stages the issue of onset and its impact on the family will also be examined.

Once again I will present a brief statement of what is expected of the normal person and family in this life cycle stage, it will precede the findings of the study.

The "Launching Of Children And Moving On" or the "Empty Neat" (McIver,1937), is a phrase which describes the activities and tasks

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[38]. The centripetal concept is not attributable to Carter & McGoldrick. Combrinck-Graham is credited with contributing this concept to the field of family therapy

of the family between adolescence and retirement. It is a time that is not clearly demarcated by any significant biological or psychological transformations. As a phase of life with distinct problems, benefits and tasks, it is relatively new. It is a product of western industrialization which has transformed the family into a more mobile and isolated entity.

Compared to pre-industrialized society, contemporary offspring leave the family at different ages and for different reasons. Parents live longer, so there is a relatively new and increasingly longer period of time when the parent's role is unclear.

The launching of children and moving on should begin during late adolescence when the family begins to nurture autonomy by allowing the adolescent to extend and recompose the boundaries of the family unit. It is a phase of life which "starts before it starts"(Nichols, 1988).

For the parents the period is generally thought to begin in the mid-forties and extend to the mid-sixties. This twenty-year period is probably the longest single period in every developmental framework. In fact, it is longer than three of the previous four (Marriage, Young children & Adolescents) life cycle periods combined. Ironically, proportionately less time has been devoted to the understanding of the tasks and norms of this period than to any other phase of the life cycle.

The tasks of this phase as with the other two in this study, include the developmental work for three generations. The parents will be expected to re-negotiate the marital and dyad system, to fill the vacuum in their lives as a couple as well as parents. This task is created by the departure of offspring and accepting the separation from their children.

Grandparents are expected to deal with a number of social, personal health and financial issues. They must get used to relying on others for things they previously did by and for themselves. They must carve out a new productive role for themselves within the family system and community, and prepare for the death of a spouse as well as their own.

The offspring should move towards more autonomy, independent decision making and responsibilities, find a mate and develop other contemporary relationships, build an adult-to-adult relationship with their parents and develop financial independence and method of sustaining that independence.

As with the other two life cycle stages, specific questions were asked to increase the probability that the theoretical concepts and tasks of this stage would be commented on during the data gathering interview[39].

There were thirteen cases in stage V of the life cycle. Forty six percent or (six all together) were married and still living with their mates. All but two of the patients in this category were male. Three patients no longer lived at home. One, currently in prison for a felony, was accused and convicted of trespassing and tampering with U.S. Post Office property. He will be called

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[39]. The questions on the questionnaire which targeted the issues of this the fifth Carter & McGoldrick life cycle stage are questions 17, 21, 22, and 23.

Anthony for purposed of identification in this study.

The other patient who will be known as Dean had been sent to a drug rehabilitation center on Long Island. He was successfully detoxified and placed in a supervised living facility on Long Island, away from the temptations of his home turf. As of the writing of this report, he still lives at that facility and has remained drug free. He attends treatment programs and for the first time in several turbulent years is complying with all aspects of his treatment. As a result, and according to both Dean and his mother, he is making steady progress toward controlling his symptoms as well as improving his social and vocational functioning.

The third patient, who will be referred to as Paul, currently lives in an adult/proprietary residence. This is a major accomplishment in terms of his history. He is stable but still symptomatic in that he continues to be delusional, mildly thought disordered and occasionally has non-disturbing hallucinations. However, he is no longer obsessed with bizarre cult activity, delusional demon worship, nor is he a threat to himself or others. He is no longer a management problem and is able to concentrate and reality test well enough to appropriately utilize the social skills he acquired before he became ill[40].

Most of the patients whose parents are in the fifth stage of Carter & McGoldrick's life cycle configuration are themselves

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[40]. Reality testing is the activity of differentiating what is real in ones perception and what is not real.

relatively stable individuals. The parents who are in this stage of the life cycle made up 43% (N=13) of the entire research sample. Seven (53%) of the thirteen were single parents, and nine (69%) of the patients were early onset victims.

The most prevalent issue observed in the transcripts of this group's responses were the issues of independence, followed by burden, flexibility and normal expectations.

On the issue of independence the respondents' statements clearly convey feelings about their predicament. One mother speaks about two of her three children, especially a son who is not a patient at the clinic where the data was gathered. However, he appears to have all the classic symptoms of someone suffering from schizophrenia. He tends to seek treatment (though infrequently) elsewhere. She says:

> He's totally dependent on me....I expected them to (referring to her daughter Henna who is a patient at the data gathering site) ....your children are never totally independent, even when they're grown, you know that... I don't know how grown yours are but I know that other women children are never totally independent. But I did expect that they would be able to go out on their own, they would have a family, they would be able to function normally and live like my Mac does.

This mother's third child has separated himself from the family, geographically and emotionally. The separation is suspected to be an attempt to insulate himself from the craziness as he puts it, of his two siblings bring to the family and his mother's tendency to "let them get away with it" as he has once said to her.

Another mother is very blunt about the issue. She says:

> My independence is to be by myself alone and do whatever I want to whenever I want to do it. I don't want anything to hold me back neither a husband or a child at this present time. When I was younger I didn't know any better. For instance, Gabriel is a hinderance, he makes me feel like am not quite independent because he is leaning on me. An when people lean on you, you don't have your complete independence. They are dependent on you, so how can you be independent.

There appears to be a poor fit between the patient's low level of independence (as defined by the parents and the researcher) and the life cycle stage of the parents. As a result just about all of the respondents' statements regarding independence reflected burden as well.

Ironically one mother whose son's independence is now creating problems for her because of her own personal and marital problems, responds philosophically. She says of the situation:

> Well I think parents should always be there for their children we just don't know exactly what will happen in life and they might have to depend on you, it depends on the situation.

But for the most part she values her independence and is aware of the burden of her son's illness. She recalls that she was once bothered by his lack of independence. This was during the early stages of his illness:

> ...At the time, when it first began I felt a great burden, but not any more. I believe that this wouldn't be for life. I still believe it.

Nine parents or 69% of the respondents in this life cycle stage openly admitted to feeling burdened by the presence of a schizophrenic child in the family. Of the remaining four who denied feeling burdened, two had mates who felt burdened. It would seem that the poor fit of the situation generates a sense of burden in most homes regardless of how mild it may be. It may be that they feel there is no escape.

Of the four who did not feel burdened at the moment, one parent had a very supportive extended family. The parent with the supportive family had not been involved in the patient's life for several years because he was in the military and lived on the West Coast for several years after the service. This parent was spared the extended, relentless demands of the illness on caregivers of schizophrenics. She was also spared the traumatic experience of seeing her "pride and Joy" deteriorate before her eyes and consequently feeling helpless to stop the process.

The other parent who denied feeling non-the-less burdened gave evidence of being burdened despite her calm demeanor. It seemed that the burden she was rated[41] to have was not a product exclusively of her son's schizophrenia, but also from having two dysfunctional children entering adulthood. This parent also has a younger teenage daughter who appear to have some form of mental retardation or emotional disorder. This mother's periodic account of events in the home involving both the patient and his sister reveals that the patient's sister is unable to control certain aspects of her behavior under certain circumstances. She has poor control of her violent impulses and receives specialized treatment for this condition elsewhere.

This mother's burden was recently compounded by the pregnancy

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[41]. The "rating" I am referring to is my own assessment of the content and tone of her responses during the interview as well as what comes from the data.

of her daughter and the subsequent birth of the first grandchild. This event generated a more acute concern by the parent about the future of her children and the patient in particular. She says to a follow-up question to Question number 26, <u>Have you had any concerns about the welfare of your son/daughter when you are no longer able to care for them as you presently do?</u>

> Oh yes, Jack is the main one because Jack, I have to be on top of Jack which I am constantly trying to teach, not teach him show him. Now he's been listening and he's been getting better and better, But it takes a lot of time, patience for me you know, because Jack was very bad and I try to show him the right road to go on.
>
> Because:
>
> ...I say, Jack, no one will tolerate his you know the way he acts and every thing. I'm trying to motivate him and get him to take more responsibility.

The F-COPES scores for the parents in stage V are interesting in terms of burden. It seems that the sense of burden is not lifted with the availability of any one type of skill, support or problem solving tool.

When one looks at table #6, one can clearly see that the parents who indicated they did not feel burdened at the time of the interview, utilized all five coping methods to a higher degree than those who said they felt burdened.

The differences between the two groups in terms of the individual methods is not statistically significant. In other words it is not statistically significant that the parents in the "no" group were clearly more likely or be able to mobilize family resources when faced with a problem or difficulty. Nor can one say that the reframing done by one group is statistically significantly different from the other and can therefore be attributed to their outlook and state of mind or something more definite than chance.

F-COPES Burden scores for parents in Stage V

Table # 7

NUMBER OF CASES	SOCIAL SUPPORT	REFRAMING	SPIRITUAL FAMILY	MOBILIZE APRAL.	PASSIVE SCORE	COMB.
Central Score	27	24	12	12	9	
Patient #3	29	25	16	11	10	91
#4	35	28	20	10	3	102
#5	37	32	13	15	9	106
#10	31	22	6	18	6	83
#11	30	42	16	9	10	117
#13	29	28	8	17	12	94
#15	13	29	4	12	10	68
#19	32	12	13	7	83	
#23	22	24	19	15	9	89
Mean	27.2	29.1	12.6	14.4	7.2	92.5

Parent's who said NO to burden

Patient #6	30	28	19	18	8	102
#8	39	37	13	18	15	122
#25	23	28	8	19	8	86
#29	27	34	13	11	5	86
Mean score	29.7	31.7	13.2	16.6	9	99

However, when all five methods were taken into account the overall method of coping between the parents who felt burdened and those who denied feeling burdened was significant (T=4.6 <.05).

It's clear that among these parents no one coping method makes a significant difference in their attempt to cope. **It seems that a whole arsenal of coping methods with a variety of coping tools is greater than any one or two strong individual methods.**

The lack of statistical significance between the scores of the two groups for the five individual F-COPES methods does not detract from the picture the raw numbers paint. Prominent social scientists have argued that "practical significance" in the social sciences may be as important as "Statistical significance" (Hinckle & Morrison 1970), and here we have practical significance. Moreover with such a small sample statistical significance is difficult to attain.

It is clear that the *no* burden group's use of reframing for example, tells a story of how they contribute to their own lower sense of burden at this time. The differences causes one to seek reasons for the difference. In doing so, a few interesting things surface, all of which will need further investigation.

As previously mentioned, the parents who indicated they felt no burden at the time of the interview appear to *utilize all of the five coping methods on the F-COPES instrument.* Not only did they employ all five methods, but their use of them was quite extensive, specifically, reframing and mobilizing family support.

In every case except one, the parents experienced the full range of behaviors exhibited by a schizophrenic. They also struggled with the patient (as did the yes group) for a significant period of time before treatment finally made a significant change in the patient's level of symptoms and they regained a sense of control over their lives. Within that period of struggle they appeared to learn that they must utilize a vast number of resources.

A closer look at both groups revealed that the parents in the *no* burden group were generally more assertive in their approach to life's problems in general. They also believed they had at least a semi-reliable backup of some kind to whom they could turn, whether that backup be a mate, ex-husband, therapist, neighbor or God. They all also had a very clear sense of self. Even the very religious parent who puts a great deal "in God's hands" is an assertive self sufficient person who has carved out an identity for herself over time. A few excerpts from their responses clearly illustrate what they have in common with the others as a group. In terms of use of other people one parent said:

> I discuss things with my husband or friends. If it is an annoying problem I would certainly get professional help....
>
> We usually talk... and work out alternatives. If we are going somewhere and someone doesn't want to go we try to accommodate everyone. It's a democratic system on certain issues but mother and father always, we always have the last say.

To the question of growth, question #20, this parent replied:

> The last five years when I've , you know gone out and developed a career. Although early years of marriage with young children I have to say I certainly learnt allot in those years.

Another parent is confident of her problem solving method:

> I give my problems a great deal of thought... We confront each other and we talk things... I can have an opinion and tell them I believe you should do such a thing, but in long run they make up their own minds... I just advise them.

Question number 26 inquires about a particular type of burden, that of being concerned about the patient's welfare after the parents' death. This was a common concern, but surprisingly, it was not as consuming and depressing an issue as I expected it would be. It appears that the parents were cognizant of their mortality and were was not yet frightened of it.

ONSET (Early):

When this group of respondents were looked at in terms of their experience with early and late onset of symptoms in their off spring, the analysis of the data revealed nothing outstanding. The early onset group seemed more burdened than those who experienced late onset. With the exception of two patients, those in the early onset group rated very low in level of functioning, this appears to be another contributor to the parents' sense of burden.

For the most part the patients were stable, and a great deal of work by both the parents and the treatment team had gone into treating and stabilizing these patients. Even though they were stabilized, their level of functioning was not high. Two patients did not live with their parents, which generally has a positive impact. Both separations were recent and took place after a very long process of education, support, and painful limit-setting by the parents, which eventually facilitated conventional treatment methods.

However, as a group these parents were stressed by the presence of the illness as were the other subgroups in the study. Social supports were low and they were not very enthusiastic in their use of spiritual supports. They rejected passive appraisal as a method of problem solving. Mobilizing family support was on the positive side but there was not a great deal of confidence in this method.

This was interesting since six of the parents were married and living non-conflictually with their mates. Reframing as a method of dealing with problems was strongly utilized.

The question raised by these findings; Has the presence of the illness within the family for a long period of time exhausted the family resources by the time the family reached this stage? The answer seems to be yes and no. As mentioned above, it depends on the availability of an array of resources, none of which needs to be a proven success by itself. The constellation, the variety, the combinations seem to do the trick. Essentially it depends on how burdened the parents and the family feel.

Cumulative F-COPES Scorers of Early onset/Late onset Cases

Table # 8

Number of patients	Social Support	Reframing	Spiritual Support	Mobilize Family	Passive Aprsl.
	27	24	12	12	9
Early onset	26.1	30.04	12.8	13.8	8.1
Late onset	32.2	28.7	12.7	16.5	9.7

Overall t=0.096 <.05

As table #8 clearly displays, the F-COPES scores are not statistically significant but they do tell a story. Once again the notion of "practical significance" comes into play.

ONSET (Late):

The late onset subgroup is made up exclusively of parents of patients whose symptoms first appeared during their mid-twenties and later. It is a combination of parents whose children achieved a certain level of autonomous functioning which includes a few adult developmental milestones such as full time employment, independent living and services in the military, etc.

In many cases the parents reported observing strange behavior during adolescence but not enough to warrant special attention. However, the peculiar behaviors were brushed off as youthful eccentricities. It is also important to note that this realization is only retrospective. One father recalls his attitude about the trouble his son tended to get into during his last year in high school. He says:

> The boy really's not a dummy, I mean.... but I didn't know it's a sickness or he was just trying to get over you know.

Rolland's typology of chronic illnesses identifies the rapidity of onset to be significant in the way the family reacts and manages a chronic illness. He says of gradual onset...

> The rate of family changes required to cope with gradual-onset diseases allows for a more protracted period of adjustment (Rolland, 1987).

All patients who were identified as having late onset exhibited full blown symptoms for the first time after their adolescence and into their adulthood stages.

There were only four late onset patients among the Stage V group. All four parents were single parents. One was a male parent and the other three were female.

Their F-COPES scores were unusual in that, for the first time in the study, a subgroup scored high on every method of problem solving. They seem to strongly believe that their use of social supports would help them deal with problems, and they seemed to rely heavily on social supports, not in a dependant way but as a resource. They did not believe that spiritual support would be helpful which makes sense since, none of them was particularly religious.

They pursued family support quite regularly even though all four were single parents. They did not reject passive appraisal as a method of dealing with problems. Reframing things in a positive light was a strong method among all except for one mother who herself was under psychiatric care for chronic anxiety and depression.

This raises questions about the long-term effect of schizophrenia on the parents' ability to problem solve and to utilize resources and maintain a positive attitude toward the problem.

The data suggest that the presence of schizophrenia can wear a family or parents down over time. Parents social supports or their use of them can, and probably is, eroded over time if these supports are not strengthened by other supports as shown in table number 6.

These parents are also fortunate in the fact that they were probably spared the stress of dealing with an adolescent who became symptomatic. Their response to the onset of the illness is similar to the parents in Stage IV during the early onset of their sons illness.

As with the parents of Stage IV, these late onset parents seem a bit naive, with high expectations of their sons.

When asked Question number 7,Using the scale of 1 to 10, how independent were you expecting him/her to be at this point in his/her life. And Question number 9, How do you feel they turned out. The reply from one father was indicative of most of the answers in terms of the hope and expectations they might still have for their son:

> Well I think he would be fully independent. At least a 10. I expect 10 plus from him.

He goes on to say:

> Well I feel that he might still be alright. I feel that you know that if he really away like now, and can really come to his good senses and decide and find something decent to do, yeah I think he'd be alright myself.

With the exception of one, every patient in this group functioned on a higher level before the parent became aware that their child was stricken with schizophrenia. One mother reports...

> I never noticed that Ali.... You see the family broke up and Ali was with his father until the age of 13 and 14...When he was living with his father his father wouldn't allow him to come and visit me. You see there was this anger underneath. Being that his father was a religious Moslem type of person. He kept saying I was a bad western woman. He said I influenced my children so he kept Ali away from me... He left his fathers home at the age of 16 and he came to me. I said I can't take care of you because you are in the custody of your father and I'll have to go to court, I didn't want to go through all of this so he decided to find an apartment of his own and a job which he did...He stayed in New Jersey for many years. He came around once a year to visit me so I would

> not notice any thing. I noticed that he was ill when he lost his job and that was when he was in his twenties. I didn't notice a quick change at all.

There is another significant difference between the late onset group and the early onset group. The late onset group functioned on a higher level for a longer period of time before becoming symptomatic. As a result their behavior when stable is less stressful for the parents in terms of management than the early onset patients. **However, the expectations of the late onset patients were greater than the early onset patients.** And the parents of the late onset patients seemed more shocked and disappointed in the fate of their children than did parents of the early onset patients. In fact, the parents of the late onset patients continue to have high and possibly unrealistic expectations of the patient. This phenomenon is demonstrated elsewhere.

RE-ORGANIZATION OF MARITAL DYAD:

Reorganization of the marital dyad requires both partners to make changes in their roles and relationship towards each other. It is a dangerous but necessary transition for the couple to make. The danger lies in the fact that the change can be precipitated by several factors and at almost any time within the time frame of Launching Children And Moving On. The child and everyone else in the family will age chronologically regardless of the emotional state and preparedness of the individuals within the family. This natural process will demand reorganization of the family constellation and of the executive marital dyad in particular. Failure to adapt will guarantee fragmentation of the system and dyad.

Most of the married parents in Stage V registered satisfaction with their marriage. A mother gives her reaction to the question:

> The most ah, I guess maybe the last five years. This is a hard question, I guess when my children were very young I was very satisfied. I enjoyed staying home and mothering. Those were very happy years when the children were very small. And then I'd say it was more difficult years when they were teenagers, and now I'd say it's more satisfying again now that everybody is more independent.

The marital satisfaction most of these parents felt, seems to be rooted in their ability to grow as individuals and accept certain things about their mates.

Independence was identified as an important variable in their sense of marital satisfaction, and the evolution of their marriage into a stable supportive mode was generally a happy one.

As previously mentioned, independence was the most prevalent variable among the parents in Stage V. For some, independence meant the maturing of their children:

> I think when my children got old enough for me to go back to work and be a little more independent on my own.

With the exception of one mother and one father, every parent among the married couples worked or was engaged in a meaningful daily activity[42].

The moving out, either physically or maturationally, of their

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[42]. The mother of patient # 13 has a permanent physical disability which makes it very difficult to ambulate. The father of patient # 11 had a massive stroke and is unable to function independently or any where near his previous level.

children allowed them to become reinvolved in work and other activities. This also helped their self confidence and sense of self-worth.

A mother describes how she and her husband were able to raise a family and remain married for 34 years. She said:

> It wasn't always like I was satisfied from the beginning with everything because we are different. Me and my husband, I a christian and he is not. So there are little things there, little things, but I can deal with them. We are very close, we know each other very well. He's close.

In response to a follow-up question about what made things work for her and her husband? She replied:

> More like understanding. I mean like my husband he has some ways that you know most women want to change their husbands you know. An I know that it's not right to a person try to change them because there is nothing you can do. More understanding.

The reorganization of the marital dyad seemed to have less trauma for the couple than expected, considering the chronicity of the situation. The parents seemed relieved that they were able to be involved in something other than the daily management and supervision of their child. There were no complaints about being abandoned or restrained by their mate when the mate branched out into outside activity.

During a joint interview with both a husband and wife, the following statements were recorded:

> Right now I feel....(pause to attended to their barking dog), like I was saying, I feel more satisfied with myself. I feel I'm accomplishing more, I'm doing more things and people are complementing me on the way I'm growing and doing more things. I've joined a theater group.

Her husband joined in:

> working has always come first with her, in other words she would say don't do that let me do it. Now she's different.

The patients mother adds to her husbands descriptions:

> Now that the kids are all grown up and you know I'm not taking care of them, doing things for them, you know I'm doing things for myself.

Her husband joins in again:

> I think we're much closer now. We understand one another's mood and needs. We understand each other.

To conclude the patients mother adds:

> I think we have grown in understanding each other better. In 1974 we began to open up, we went to marriage encounter and it opened up a whole new kind of outlook on us and our children. I became more flexible.

This particular couple scored very high in social support, in spiritual support and in mobilizing family support. Still on the positive side, reframing things into a positive light is also consistently used by this family. Passive appraisal is a rejected problem solving method.

F-COPES Scores For Couple That have

A high degree of Marital Satisfaction

Table # 9

Number of patients	Social Support	Reframing	Spiritual Support	Mobilize Family	Passive Aprsl.
Central score	27	24	12	12	9
Patient #4	35	28	16	11	10

FOCUS ON SELF:

Focus on self was a code for a phenomenon observed during the review of the respondents' transcripts. According to the Carter & McGoldrick framework, it is normally part of a task associated with the earlier life cycle stage The Family With Adolescents. It is akin to, but not the same as, the self actualization some individuals seek during an earlier time in the life cycle and through more formal methods such as therapy. However, this is not to say it is exclusive to that stage. In fact every stage requires some focus on the self as individuals must reevaluate themselves and make the required changes necessary to grow. In this context the focus on self was observed as being significant to the single parents

Among those who are not married, the evidence of addressing the issue is clearly present, but their success is more difficult to determine. Many of their comments were made while reflecting on the burden they felt. For example, a mother responds to another question but focuses on herself and expresses her burden in caring for her son. She says:

> I know that he is doing these things because he is not well. But at the same time I have problems too, I'm not a 100% emotionally healthy person who is as strong as some mothers. So I'm not as strong as I would like to be, maybe if I was a strong person emotionally I would be able to handle Ali's problems much better. But there are times when I am.. we clash because of my insecurity, anxiety and fears. I don't turn out to be as flexible.

The F-COPES scores for this mother are interesting in light of what she says about many issues including the issue, of focusing on self as a healthy and expected task.

She is high in the availability social supports. This mother has one friend with whom she occasionally spends time. She has few other friends. Because she is a bright, pleasant, and attractive person, she is recognized in her immediate community. However, most of her social contacts are made through agencies such as the Baltic Street Clinic.

F-COPES Scores For Case Number # 10

Table # 10

PATIENT #	SOCIAL SUPPORT	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRAL.
	M= 27	M=24	M=12	M=12	M=9
Patient #10	31	22	6	18	6

She is positive about spiritual supports but only slightly, and she is also positive about passive appraisal. This is not surprising since she is frequently anxious and depressed about the stresses and strains in her life.

Reframing and mobilizing family supports are very positive problem solving methods for her. Her mobilizing family support's scores is a bit surprising since this mother is generally isolated from her children and extended family. It is quite possible that her perception of mobilizing family is an ideal more than a reality even though the F-Copes question clearly ask "When we face problems or difficulties in our family, we respond by:" she identifies it as something she is able to do. Elswhere she has said that her children visit her quite often, however, they are reluctant to come when Ali is home; and he is home most of the time. In fact he usually goes out only to keep clinic appointments or to purchase something for his mother at the corner bodega. Consequently when her other children visit and he is home they are very uncomfortable and tend to rush out.

This mother is not as disabled as she sometimes feels. She is isolated and uses few supports. She has not recovered from the failure of her marriage and the abusive manner in which her ex-husband treated her.

Another single parent who has two children suffering from schizophrenia, demonstrates how and why she focuses on herself. Her response to Question number 23 clearly paints a picture of her frustrations and the burden of dealing with the illness, especially at this point in her life. She says:

> Well actually it was supposed to have ended when my children reached adulthood. But like you see and I said, it doesn't because little troubles little kids, big troubles big usually big problems. I would like a life of my own. Right now I have it. I go places with my group that I'm in Yea well I'm looking forward to being able to go on with my life and go out when I can go on trips.

It seems that the presence of a mate makes a great deal of difference. Based on the reports of these parents, the presence of a mate seems to allow one partner the luxury of time for positive reflection on life. *In addition the presence of a mate seems to mitigate the sense of being saddled with the problem by one's self for the rest of one's life.*

When the F-COPES scores for the married parents are compared to the single parents the sense of burden can be appreciated. It *seems that it is simply more difficult to be a single parent with a schizophrenic child than a married parent with a schizophrenic child when the qualitative data is examined.*

Comparative F-COPES Scores For Single/Married Parents

Table # 11

Number of patients	Social Support	Reframing	Spiritual Support	Mobilize Family	Passive Aprsl.
	m=27	m=24	m=12	m=12	m=9
Single Parents	27.7	28.7	9.7	16	9.4
Parents with mates	28.3	32	14.6	15	7.8

When married and unmarried parents F-COPES scores are compared for their "practical Significance". It seems that both groups utilize social supports but the parents with a mate tend to be more likely to do so. Both groups appear to utilize family support virtually equally. Parents with a mate seem to utilize reframing very regularly and more so than single parents. This may imply that the presence of a mate contributes to a more positive and optimistic view of a problem situation.

The parents without a mate tended to not utilize spiritual supports. A closer look at the individuals who make up this subgroup revealed that they were not very religious. In fact some of them rejected religion in general. Even the high score of one extremely religiously preoccupied parent did not bring the groups' scores closer to a neutral or "Moderately Agree" score. However, the parents with mates did utilize spiritual supports. And finally, passive appraisal was rejected by couples but moderately utilized by single parents. The implication that the single parent is more likely to look to luck and other passive problem solving methods is understandable.

These findings strongly suggest that having a mate is preferable to not having one in terms of utilizing a variety of problem-solving methods in managing schizophrenia. These finding seems, to give credence to common sense. If one must deal with an extremely draining chronic situation without the steady support of someone like a mate, it seems reasonable that they themselves are more likely to become depressed.

This finding also seems to support Agnes Hatfield's (1979) findings in her 1979 survey of families of the mentally ill. Hatfield reported that among the things families wished most for in terms of dealing with their mentally ill offspring was respite and someone with whom to share the strains of the situation. That person ought to be someone who knows the stresses and strains of the situation. In this respect, single parents are clearly at a disadvantage.

ACCOMMODATE GRANDCHILDREN:

By this time in the normal life cycle of a family or couple, many couples are in a position to become grandparents. The couple is required to once again adjust to a role and structural change. Once again their relationship to each other and every one within the family constellation changes and in the ideal situation they must move further from center stage within the family than they have ever been before.

However, this issue was rather straightforward. As mentioned above, a question was designed to target this specific issue. Many of the parents were already grandparents from their other children. The vast majority of parents welcomed the idea of being a grandparent. It was one of the few questions on the entire questionnaire which stimulated a spontaneous upsurge in affect.

One parent who is already a grandparent and generally enjoys this role, first reacted in the negative to the question, she went on to explain herself:

> No way! I love them, I take care of them, they come over when they have birthdays and parties and things like that. But if somebody was to ask me, here is a baby take care of it I wouldn't want that type of work I don't have that type of patience. I have two grandchildren by one of my daughters. One of my daughters has another one and one of my sons have another so that's five.

This parent is a single parent whose schizophrenic son currently lives with her and remains a burden because of his only partial compliance with treatment coupled with the severity of his illness. He hardly leave the house except to keep bi-weekly appointments with his therapist. This parent feels shame and burden as well as guilt for her son's illness.

Another parent was luke warm to the idea. She said:

> I never had that in mind, I never had those things in mind. I feel if it comes it would be alright but I never think about that.

The follow up question was. Do you have any grandchildren yet? Her reply was:

> No not yet. I don't have any ah.... I'm a little depressed right now because, I don't know if David told you, he lost, I lost my oldest son in march (1990), march 20th. Right now I'm not as , I'm a little bit under the weather sometimes. I didn't get back to myself yet.

Two parents were emphatic about their rejection of the idea. Both were single parents and both were relatively young even though they belonged to different life cycle stages. Both parents were still struggling with the stabilization of their schizophrenic child. Their verbatim response to the question was ...."Hope not, No", and "No".

One parent was not looking forward to it. However when it happened she was pleased.

There were two other who responses to the question, once again from single parents. One was still in the fourth stage of the life cycle and her son had recently become symptomatic. On an important level she still thought or felt her sons were children. She was preoccupied with helping her child get back on his feet.

The other person whose response was negative also has young children who she must see through this difficult and unfamiliar situation. She also seem to realize that both of her children may be incapable of being good parents simply because of their emotional and intellectual impairment. Her reply was:

> No, I'm a grandmother now. I'm really in shock because I never expected that from my daughter.

All three life cycle stages are represented in these negative responses. However the one parent who is in the sixth stage of the life cycle does not express enthusiasm partly because she is still depressed about the loss of an older son and is still mourning his death.

The majority of responses were of this nature:

> Yes I really was. Naturally I think every woman would like that. Then again, my daughters is.... My daughter-in-law Brenda and Mac she was having a lot of problems with her ovaries. They don't, Mac doesn't talk over any thing on that subject with me at all. He says he feels that's up to his wife and him, It's a very personal thing and I accept that.

> Oh yes I cant wait. Yes I can't wait. And my husband too, he loves little children, he cannot wait. And I pray that God will let him live to see.

Once again being a single parent of a schizophrenic child seems to be a major handicap when one has to deal with the normal developmental issues such as Launching Children And Moving On. Having a mate seems to allow a parent to look forward with enthusiasm to this important life event.

DEALING WITH DISABILITY AND DEATH OF GRANDPARENTS:

The task of dealing with disability and the eventual loss of the grandparents in the family did not appear to be major issues with these respondents. This was true for the parents in the fifth life cycle stage, Launching Children And Moving On, as well as the entire sample.

Four of the thirteen respondents in the fifth life cycle stage were dealing with disabilities at the time of the interviews. Three had mates who were permanently disabled, and one was disabled herself.

All of the respondents were burdened by the disability of their mate. However, the presence of their child's mental illness did not seem to make them any difference from the other respondents in the sample. The F-SCOPE'S scores indicate the parents in stage V who are dealing with a disability are strong users of social support, where as the entire sample of thirty parents do not feel strongly about using social supports. The score for family support among the four subjects dealing with a disability is the highest of any subgroup in the entire sample A score of 17.5 was not surpassed by any other group.

These families also utilize all methods of problem-solving the F-COPES instrument examined. This is supportive of similar findings mentioned above in regard to onset.

<u>Parents With A Disability In Stage V Vs. The Entire Sample</u>

Table # 12

Number of patients	Social Support	Reframing	Spiritual Support	Mobilize Family	Passive Aprsl.
	m=27	m=24	m=12	m=12	m=9
Disability Stage V	33.2	33.7	14.2	17.5	10
Entire sample	23.4	29.1	11.7	13.9	8.3
t=-19.5 <.05					

CHAPTER SUMMARY

This chapter highlighted the significance of burden to the life cycle of the family with a schizophrenic offspring. By the time the family has entered this phase of life the patient had already been ill for a considerable amount of time and the wear and tear of the situation had began to show. The adaptability and resourcefulness of the families involved were also documented.

CHAPTER VI

STAGE VI: THE FAMILY IN LATER LIFE

(Accepting the Shifting of Generations)

INTRODUCTION:

This chapter focuses more on the parent than the patient. As with the previous chapter the data will be preceded by a description of what most persons or families must deal with as they reach this phase of the life cycle.

Because Stage VI may be considered the last phase of the life cycle (depending on the model one employs), it seems appropriate to focus primarily on the tasks of the family from the perspective of the oldest and founding members of the family. The family unit as an entity begun with the parents and must end with the parents. Offspring may have gone on to start their own families, but their generativity is not central to the process which began shortly before their conception and birth.

Gerontology, the study of aging, has become a popular topic in the research and lay community. This is due largely to the change in the nations demographics. The baby boomers born during the 1948 to 1963 period began to mature and enter middle age. The economic, social, political, demographic and psychological reality of their own mortality and the aging of their parents has prompted growing interest in this area.

There are many long standing myths and misconceptions about the advanced stages of the life cycle in relation to psychological and social functioning. These myths and misconceptions include the belief that most elderly are isolated and have no family, and/or that they chose to be isolated for a number of reasons. Another is that the family and family structure of the elderly is brittle and rigid in interactional patterns and general attitudes. Finally, there is the theory that the elderly person as an individual is rigid and inflexible.

These myths are not supported by the facts. Many individuals entering old age, as well as the family units headed by someone entering old age, are still vibrant people. The elderly have specific tasks to perform, and contributions to make. Unfortunately, our society has not figured out a way to systematically take advantage of that vibrancy, experience and wisdom.

That energy, wisdom and surprising flexibility makes itself useful in many ways. Because the majority of American women of working age are now in the work force, more and more able grandparents are taking on child care responsibilities again. They are also a large part of the volunteer work force. They are taking on part-time jobs with reduced or no benefits, and they are simply staying on the job much longer than heretofore. In addition, most elderly parents live independently of their children and choose to maintain their own residence or at least a residence separate from their children. Ninety-five percent of the elderly people in the United States live independent non-institutionalized lives. They value their independence and are very creative in maintaining it. There are many reasons for this, including a desire to avoid becoming a burden on their children (Butler, 1989), and most importantly they simply want to maintain their privacy and autonomy.

Because most elderly parents and their children continue to desire a connectedness or at least "Intimacy at a distance", (Walsh, 1980) the emotional ties between them must endure a number of transitions as they seek to find a satisfactory arrangement.

There are a number of major stressors facing the elderly individual, couple and family. These issues include retirement, the change in one's role in the family system and failing health. In most cases economic vulnerability, the loss of one's mate, and grandparenthood are common stressors. All of these stressors must be dealt with in one way of another.

With the launching of the last child, the family in later life converts back to its original structure which is a dyad. There is a refocusing on the marital issues which for many was anticipated and in many cases, looked forward to. Many couples experience increased marital satisfaction shortly after the last child has been successfully launched (Rollins & Feldman, 1970; Lowenthal, Thurner, & Chiriboga, 1975).

Movement through this stage can also be a traumatic transition for the couple, especially if they had not resolved certain marital issues prior to reaching this state. The loss of the maternal role can be particularly stressful to the mother especially if she has not developed an additional and satisfactory role for herself in addition to her maternal role.

When an elderly couple's child has schizophrenia this transition is threatened and further complicated. As a result the ability to deal with the issues of later life can be seriously compromised. The family unit may continue to exist but the parents as individuals may not be successful in dealing with what Erikson calls "Ego Integrity Vs. Despair, the final developmental task of the individual.

The study sample contains fifteen parents who are in the final stage of the life cycle. Eight openly said they felt burdened by the presence of the illness. Seven denied it. Nine parents were single including the only two males parents in this stage.

Number of Parents In Stage VI

Who Felt Burdened Vs Those Who Did Not

Stage # 13

	Burdened	Not Burdened
Father	3	2
Mother	5	5

The most prevalent experience reflected among the subjects in this group was burden, followed by flexibility and then the issue of maintaining their level of social, physical, emotional and economic functioning. There were also indicators that the subjects did not have a technical knowledge of what schizophrenia was or how long the illness would last. This lack of knowledge seems to reflect both who they were as individuals and as a chronological group. It also reflects the state of psychiatry and its education of the general public to mental illness. Despite this, these parents were basically optimistic. At the same time, their problem-solving skills were not up to the task of managing a schizophrenic child. It is not clear, however, whether their skills eroded over time and, or if they had ever acquired them in the first place.

Many of the normal life cycle tasks such as dealing with the loss of loved ones and life review were less prominent and conscious in these parents' minds.

As with the other two life cycle stages examined in this study, the questionnaire contained questions aimed at eliciting responses about the relevant issues of this stage.

With the frequent appearance of burden and the infrequent appearance of problem-solving indicators in the transcripts of the interviews, it seemed reasonable to look closely at the problem solving methods of this group. How do they manage, why do they manage, and for those who do not, what keeps them from managing? If they were burdened, why or what caused their problem solving concerns to diminish?

The transcripts served two purposes here. First it displayed and alerted me to a possibly important phenomenon which requires further investigation but using a different research method. Secondly it will be used to once again highlight the findings of the analysis the F-COPES analysis which it spawned.

This group's F-COPES scores were surprising. According to the F-COPES scores the parents in this stage of life were significantly limited or deficient in their use of problem-solving techniques.

However, before we go any further it is important to once again review a few basic beliefs about schizophrenia and social support in general.

First, it is well established that families with a schizophrenic member tend to be and feel stigmatized, and they also tend to become socially isolated. They feel burdened financially, emotionally and socially. In terms of the normal life cycle process, in this culture, as people pass their prime and become senior citizens, their social network and supports tend to shrink. They tend to get more out of the quality of the relationships as opposed to the quantity. They also tend to resist giviing up their independence and are concerned about becoming a burden to their children, other relatives, friends and acquaintances.

The data and interpretations presented in this section should be understood in the context of these well-accepted facts.

Average F-COPES Scores For All Patients In Stage VI

Table # 14

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=9
15	19.6	28.7	13	13.2	8.4

The mean F-COPES findings in table number 13 paint a picture which is clearly supportive of current thinking about this age group. As previously mentioned, It is a well-accepted belief and that by the time a person reaches this stage of life, their social network has shrunk for a variety of reasons. Some of these are positive, others are not.

As the data suggests, the F-COPES Social Support variable with a mean score of 19.6 suggests that these 15 parents are not likely to use social supports when dealing with problems and difficulties. Their score indicates that they are a little less than moderately opposed to this tactic of problem- solving.

Their moderately positive use of reframing problems into a more positive light to avoid becoming discouraged, may reflect their sober wisdom and valuable life experience in dealing with problems. This tendency certainly speaks to the challenge of Erikson's Integrity Vs. Despair. It seems that these subjects overwhelmingly chose integrity.

Most of the respondents were not very religious even though they all believed in God. Their use of spiritual support which was primarily in the form of institutional services, was positive but barely so.

Finally, this group's rejection of passive appraisal coupled with a positive attitude, (but not overwhelmingly towards mobilizing family supports), suggests a tendency or desire to maintain their independence and not be passive and allow luck to control their destiny. This profile was maintained despite the prevalence of burden in the dealing with schizophrenia.

When scores of Stage VI are compared with those of Stage V, the significance of Stage VI F-COPES scores and the interpretation of them becomes even more meaningful.

COMPARATIVE F-COPES Of Stage V with Stage VI

Table # 15

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=9
Stage V	28	29	12.6	15.5	8.6
Stage VI	19.6	28.73	13	13.2	8.4

It is clear that there is a sizable difference between the two groups in their use of social supports, but very little difference with the other problem-solving methods. Stage V parents clearly utilizes social supports more frequently than those in stage VI. However, even stage V's social support scores were not that outstanding by themselves. These differences are not surprising and they add support to the previous interpretation of Stage VI social support numbers. This suggests that something takes place with these families whenever either the predictable age factor or the age plus schizophrenia cause the noticeable reduction in social supports.

There are almost as many parents in stage VI who feel burdened as there are those who deny feeling burden, (N=7 & 8 respectively). There are also a similar proportion of parents who feel burdened in stage V as there are in stage VI. It seems that neither group has greater feelings of burden.

Another feature of these scores is that the social support score of 17 for burdened parents in stage VI is significant not only in that it is less than the no burden parents in that stage, but it was well below the mean score of 27. This suggests that these parents strongly reject social support when faced with a major problem in the family. It is not only an indication of less support, but the absence and possible unavailability or refusal to use support on the part of these parents.

Reframing is virtually the same for both stages even though there is a perceptual but insignificant decrease in reframing from stage V to stage VI among the no burden parents. However, there is an increase in reframing among the burden parents.

As social supports decrease from stage V to stage VI, reframing increases among the more burdened parents. This suggests that the increase in reframing may be an attempt to compensate for the loss of social support. The parents must now have a slightly different and positive perspective on their situation. This reframing could also be a form of denial. However, most of these parents were very candid and realistic in their attitudes toward their own mortality, and their understanding of their child's illness and situation. They also seemed to have learned something which forced them to be more realistic than many of the parents in the other two stages.

Even though the data do not provide definitive proof, they suggest that the presence of schizophrenia in an off-spring, coupled with the natural and average course of the aging process, may have something to do with the very noticeable drop in social supports from one life cycle stage to the next.

This, along with other empirical findings and theoretical interpretations, supports the notion that the presence of schizophrenia does not fully block or permanently stop the achievement of life cycle tasks and movement. However, its presence does seem to make the successful negotiation of certain tasks more difficult.

Comparative F-COPES Scores For Parents in Stage V & Stage VI
Who Felt Burden And Those Who Did Not.

Table # 16

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=9
Stage V Burden n=9	27.2	24.8	12.6	15.1	8.4
Stage V No Burden n=4	29.75	31.75	13.25	16.5	9
Stage VI Burden n=8	17	29.1	12.1	11.1	8.5
Stage VI No Burden n=7	25.5	27.1	14	13.8	8.1

A less gracious interpretation of the phenomenon is simply that the parents drop in social functioning and the increase in reframing scores among the parents who felt burdened is simply a result of "burn out". The burden of caring for a schizophrenic child has simply caused the parents to give up. However, the transcripts do not support that discouraging notion.

One parent, for example a father, who was struggling to maintain his self-respect responds to question number nine which reads: <u>How do you feel your child turned out?</u> was reminded to comment only on how he felt about himself given the situation. His reply was:

> Very negative but I console myself. I console myself by facing life as it is, I am not the only person in a position like this.

This parent rejects feeling sorry for himself despite his lack of success in controlling the threatening and destructive behavior of his symptomatic and treatment-resistant son. This man's F-COPES scores reveals a clear consistency between his statements, the clinical background of the case, and his scores on the F-COPES instrument. It is clear that he does not have a great deal of social support. He believes in God and he perceives himself as having more support than the group to which he belongs. This parent's score of 21 for social support is significant not only because it is on the moderately rejecting side of 27 which is the neutral score. It is significant because this parent is still capable of mustering up significant social support if he so chooses. He clearly chooses not to, in fact the history of this case indicates that he is very independent and according to his son's chart has clearly said on several occasions he does not want to burden other people with his problems.

F-COPES Scores Of Case # 24 And The Combined Scores Of Stage VI

Table # 17

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=8
Case #24	21	36	14	15	12
Group VI Average	19.6	28.73	13	13.2	8.4

His wife is very religious. He has some family supports which comes primarily from his wife who is terrified of their son[43], and their daughter who is a high-functioning married woman.

His reframing scores, which are statistically significantly different from the neutral score and the group score as well, reflects his strong desire to remain socially independent.

He is neutral about passive appraisal and this is consistent with the clinical history of his involvement in his son's case. This parent goes through periods of aggressive attempts to do something only to be beaten back by the realities of the situation. He has periods of passivity and periods of assertiveness. After he recovers from his last setback he tries again.

His response to question number five, which is How do you define independence, not only defined independence but gave a glimpse into his problem-solving philosophy:

> To me an independent person must be willing and able to shoulder every burden of life and make it as simple as they can.

---

[43]. The son allegedly tried to rape her during one of his severe psychotic episodes. Patient denies the charge.

There are many aspects of this parent's profile that are typical of the stage.

I next asked the question, are these numbers, and verbal accounts similar when the single parents are compared to the married parents? Analysis of the data on the single parents, compared with the married parents, revealed an expected trend which is consistently developing in the rest of this study. Once again it seems clear that the presence of a mate is extremely important in surviving and living with a schizophrenic child.

When the F-COPES scores between those who feel burdened and are married and those who feel burdened and are not married are compared the following is observed.

The scores in table 16 suggest that married parents utilizes more social supports in their problem-solving than those who was not married. In fact, this is true whether they are burdened or not. They also did more reframing into a positive light than the unmarried parents, suggesting that the presence of a mate allows for a more positive perspective. It does not suggest that the parents will have a positive perspective on a problem; it simply suggests that it will be less negative and pessimistic.

Comparative F-Cope Scores Of ALL Stages

Married Un-Married No Burden & Married Un-Married Burdened Parents

Table # 18

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=9
Married no burden	23.5	28	15.5	13	8
Unmarried no burden	22.2	26	13.4	14.2	8.2
Differential	1.3	2	2.1	-1.2	.2
Married burden	17.8	29.2	13.2	13.8	9.4
Unmarried burdened	15.6	29	10.3	11	9
Differential	2.2	-.2	2.9	2.8	.4

In fact, when all the scores are examined as they appear in table 16, these families are consistently low in social support whether or not they have a mate.

When the same comparisons are made for the parents in stage VI the following is observed.

It seems that the parents with mates once again did better in terms of utilizing a variety of problem solving methods.

F-COPES Scores for parents in stage VI

Married Un-Married No Burden & Married Un-Married Burdened Parents

Table # 19

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=9
Married	23.5	28	15.5	13	8
Married/Burden	17.8	29.2	13.3	13.8	8.2
Unmarried	22.2	26	13	14	8
Unmarried/Burdened	15.6	29	10.3	11	9

Among the parents in this stage who are married and have other children, all but one of the other children had severed relationships with the family. In doing so, many put great geographic distances between their family and themselves. This is primarily because of the patient, and seems to be true of the non-married parents as well, reflecting another loss of a potential support to the parents as they enter advanced age.

The married couples who did not feel burdened also scored higher in F-COPES than those who did feel burdened. (See table # 19)

This suggests that *having a mate does not insulate a parent of a mentally ill child from feeling burdened. However, when a parent does feel burdened, having a mate seems to be extremely helpful in shouldering the burden.*

Early onset of the illness consistently produced a sense of extreme burden. Where as with late onset there were more parents who did not feel burden than there were who feel burden. As a result, *the combination of having a mate and having a child who developed schizophrenia later on in their developmental process appears to be least burdensome.*

Late Onset Patients With Mate/Without Mate

Table # 20

# OF CASES	SOCIAL SUPPORTS	REFRAMING	SPIRITUAL SUPPORT	MOBILIZE FAMILY	PASSIVE APRSL
	m=27	m=24	m=12	m=12	m=9
Unmarried	27.4	26.8	13.8	13.8	6
Married	18.75	29.5	16.75	13	7.5

Patients' Level Of Functioning:

Table # 21

Late onset unmarried	6.7
late onset married	3.5

1=superior functioning, 7=Grossly impaired

This is particularly true when looking at the level of functioning scores. When The level of functioning scores are combined with the F-COPES scores, a different interpretation of the numbers emerges. The parent's low score in social support may indicate the presence of a self generating support, and may be interpreted in negatively as well. However, the critical variable is the functioning of the patient and the couple's ability to move on with their developmental tasks. The parents in the married group are moving on.

MAINTAINING OWN/COUPLES FUNCTIONING IN FACE OF PHYSICAL DECLINE:

Most of the parents in this category were in relatively good health. One mother had a chronic and potentially fatal heart problem. Her story is an interesting one. Statements from her have already been used in this paper.

> This is a 79-year-old attractive widow whose life has been one struggle after another. As mentioned in another chapter, she emigrated to this country from Latvia. She was educated there but found it difficult to make a living, and in this country she worked in factories, as do many immigrants. She basically made it on her own with some help from the Latvian and Russian societies that were set up to assist fellow Latvians in her situation.
>
> She married at 40 in what was basically a loveless marriage of more function than substance. He husband turned out to be an eccentric mean-spirited man who hoarded things and found it difficult to share with his wife and son. After suffering abuse from him she decided to once again go against the grain of her customs and traditions and separated from her husband. The arrangement was an interesting and unusual one. After she declared her verbal separation from her husband, they continued to live in the same house for over one year until she could afford to move out.
>
> Bowing to the pressures of her community she attempted reconciliation with her husband for a short period of time. She conceived her son during that attempt at reconciliation. The reconciliation failed in terms of generating lasting warmth between the couple. However, they stayed together until her husband's death several years ago. He was probably schizophrenic.
>
> Though her husband eventually stopped threatening physical abuse, he continued to behave in a bizarre

> manner by hoarding things in <u>his</u> room to which no one gained entrance. He was also emotionally abusive toward the son, who grew up hating his father.
>
> Shortly after her husband's death and when she believed she was free of at least one major problem in her life, she was diagnosed as having a major heart problem.
>
> A pacemaker was placed in her heart and many of her activities were curtailed, at about that time her son became increasingly symptomatic. Like his father, he had been an alcoholic and his behavior was become bizarre.
>
> The patient did not hoard things as his father did; instead he collected people. He would bring home stray drunks who would stay way beyond his mother's willingness to have them. He also began to exhibit self-mutilating behavior and more direct suicidal activity.
>
> This parent spent most of her time responding to symptom related behaviors and situations while her health deteriorated.
>
> Five years ago she and her son were asked to participate in a demonstration project in which she would be offered a great deal of clinical support, education and guidance in exchange for a two-year participation in the study. She accepted as did her son. Their participation in this project for the first time gave both the patient and his mother continuity of care which the patient could not escape. It also gave her tremendous support and back-up.
>
> The patient responded positively to this treatment despite numerous hospitalizations. His mother received the support she desired which allowed her to attend to many life cycle issues. She is still in that process of attending to issues held at bay for decades.

This history illustrates the strength and resilience of some of the parents in this study. It also demonstrates how many developmental or life cycle tasks are delayed, slowed down, but not completely stopped by the presence of schizophrenia.

In response to the issue of maintaining one's function in the face of physical decline, this mother's situation is representative of the group. She and most of the parents were reluctant to talk about their physical health, though there were a few exceptions. One man who spoke very poor English, was almost stereotypic of the grouchy old man, and almost incoherently said the following about his physical health and medical history:

> When I was in hospital, I've been through a lot of things. Two operations in my spine, the last time I came home from the operation was the 4th of August in 1989 last year and in 1988. In 1983 I had another operation, 1983 yea, in May 1983 it didn't do a lot of good because I was come to the state I couldn't stand up. I used to just sit down. The two operations it got a little straighten out.

This was more of a life review and lamentation of his past pains than of any current concerns. He is a very frail man who uses two canes to move around and he is severely limited in his mobility. But like many of the parents in this study, he seemed determined not to be depressed about it and not to focus on it in a negative way. For example, he recalled a few things from his past, when asked How do you go about solving problems as an individual. His reply was:

> Really I not good to solve problems. My wife used to take care of every thing you know. I was dependant on her. Now that she's gone I'm sort of lost but I manage. But i'm not good at it. I did my own thing I look after my baby plants whatever I got to do it. I do the shopping I plan to keep going, really. I'm not a young boy I was always strong, I must have been good body builder.

Functioning in face of physical decline seemed more in the parents' consciousness than strictly health issues.

The mother of a very symptomatic young man who herself has had a hard life is very concerned about her husband's health. He has numerous physical problems and is several years her senior. She talked about the frequent emergencies she has to deal with in her family:

> The last time it was my husband. We went out to do some shopping and my husband said wait for me here I'll be back in a few minutes. I forgot something and I started to wait and wait. When my husband didn't appear I then decided to go back to the home. I found mt husband had taken the valium along with....? When I feel my husband goes too much to the basement or something I go after him.

This parent is referring to a suicide attempt her husband made when he allegedly realized that his son, the patient, had a mental illness. There is a family myth that this parent has kept her son's mental illness from his father for decades so as not to discourage him. It is safe to say that the patient's father knew of his son's mental illness but was also consumed by his own depression.

It seems that this mother's statement sums up the issue of maintaining functioning in face of physical decline. This mother is the elderly mother of a previously-mentioned patient who became symptomatic at a very advanced age. She was beaten by her drunk husband in front of her neighbors. Her mother said rather bluntly:

> I don't have time to think about anything but I always have Lucy on my mind, Lucy and her son, that's the only thing on my mind.

Many of the parents in this group have serious physical problems. One mother has advanced stage diabetes, but she seems to have no interest in talking about it. Another father recently lost his eyesight and is working hard at adapting to the situation. His condition raised many concerns and issues for him as well as his family and especially his wife upon whom he had become more dependant. He has also been diagnosed as having diabetes. This development was felt as another major blow to a family that has already suffered numerous tragedies, including the sudden death of a 40-year-old member.

SUPPORT FOR A CENTRAL ROLE OF THE MIDDLE GENERATION:

There is some evidence that support for the central role of the middle generation is an issue of importance to some parents. It seems to be pertinent only when the parent has other offspring as well. This observation is complicated by the fact that most of the offspring of these parents have gone on to make a life of their own.

Since many of the patients have parents who are now in, or entering old age. The issue of support for a central role of the middle generation is an important one. This is true because schizophrenics especially those who remain symptomatic for decades usually do not marry and have children. **As a result, those who should have been assuming the roles and responsibilities of the middle generation are not doing so.**

For the children who are not afflicted with schizophrenia, they tend to have no interest in filling the role of the middle generation. In short, there is not much of a role in terms of quality for the middle generation when schizophrenia is involved.

The responsibility is often rejected or reluctantly accepted. As a result the parents' generation is not afforded the luxury this shift in structure and function is supposed to offer members of the family. And as previously mentioned, many of the children who are not affected chose to have as little contact with their family of origin, primarily because of the schizophrenic sibling.

A father explains the situation regarding two of his sons. This father and his wife raised three children. All three including the patient are male. This is a pleasant, middle class family of Italian descent. They reside in what was once affectionately referred to in the neighborhood the little Italy of Brooklyn, so dubbed because of the high concentration of Italian immigrants who settled there. Once settled many of them never left the neighborhood again. There are stories of people who literally never crossed Atlantic Avenue, a major street and unofficial dividing line between "Little Italy" and downtown Brooklyn.

Since gentrification, many of the old residents have passed away or become too old to manage their property and have sold their homes. The boom in real estate during the late seventies through mid nineteen-eighties also facilitated the change in the neighborhood.

Some of their children have been able to break the psychological hold of the family and extended family and have moved off the block and in some cases out of the neighborhood.

This respondent, who takes pride in the fact that he was able to purchase a home for his family, was not affected or seduced by large offers to sell his home. He looked at his home as something to pass on to his children. At the time his son's condition was not expected to last as long as it did. This father's intention was to leave the house to his children who would evenly divide the estate once he and his wife passed away.

Now that his son is chronically ill and his other two sons are doing well on their own, he says about his schizophrenic son:

> I had no concept at all, of course I really didn't understand it that something was ever wrong with him. I had no concept.

He goes on to say:

> I didn't know that much about mental illness. Well all I was interested in at the time was finding out what was wrong with him and getting it cured.

His other concern was simply to have his children closer and more supportive of each other. His two sons have removed themselves not only from the neighborhood but from the family because of the patient's behavior. They do not understand what is wrong with him. They feel it is a character flaw, that he is lazy, that, like allot of other lazy people who live off the government, he just does not want to do for himself.

These feelings are interesting in that they are maintained despite the realities of this family's life. The fact is that this patient has been working at a full-time job for the past eight years, prior to his last hospitalization and recovery period which lasted several months. He also worked for a well-known bakery. This split within the family pains the patient's father. One of his wishes is to:

> Get the family to get along and get them financially security.

As it turned out his other two sons are financially secure through their own efforts, and the role he now sees for them is to make sure that the patient is taken care of once he and their mother pass away.

This parent wishes the family would stop drifting apart. In response to question, Has your family been spending more or less time together recently. Are they becoming closer or drifting apart? He says:

> Have we spent time together? The whole family, all my sons? All my sons are scattered. One in Connecticut one in Jersey. We hear from them from time to time but all at once, hardly a family affair.

In terms of his own future and the role he has for his sons he says:

> Well I'm looking forward to retirement and sooner or later I would like to have all of my children be on their own.... As a matter of fact we have provided for Simon in our will because he is the only one that isn't attached, that has no wife. So we left the house for him so no body would throw him out or nothing like that.

His concern is that his sick son be provided for and not be ignored or abused by his siblings.

Another parent, a mother this time, is clearer about her concerns for the middle generation. Her own mother recently passed away and her ill son has finally begun to respond positively to all aspects of treatment. In fact, he is in a work training program and is doing quite well. This mother, like many other parents of multiple children in this sample, must deal with offspring who has separated themselves from the family because of the siblings illness and their inability to deal with the situation. Unlike their parents, they have more choice since one of the options is to simply not deal with the problem.

She refers to her other son as "the other guy". In response to question number 12 What are some of the major concerns for you as a parent at this time in your life? Her reply was:

> The other guy who is independent. He's not married either and I want him to settle down too. I often mention it to him and it seems that every time I bring it up the subject about getting married he shuts me off, He's 34. They're both old enough to get married, all their friends are married.

All the parents in the study seem willing to be supportive of the middle generation having a central role. Unfortunately that does not seem to be on the minds of the middle generation, and the reason seems to be connected with the presence of schizophrenia in the family.

There is one exception to this pattern. A seventy-five year-old father whose son worked on Wall Street as an apprentice trader before exhibiting symptoms of schizophrenia, takes great pride in his three daughters, all of whom are close to the patient and their father. This parent relies on his daughters to take care of the family business which they do without resentment or burden. He accepts the fact that at 75 he has become dependant on them. He says... "I discuss everything with my daughters. They're pretty level-headed". As a result he has passed on the responsibility of caring for the patient to his daughters. He goes on to say:

> I'm not looking forward to anything except to see him get better and be more independent....Like I said we are a close knit family I don't think his sisters will abandon him.

Maybe being female has something to do with a sibling's tolerance for the illness and the care-taking that it sometimes requires from the family.

LIFE REVIEW:

Each stage of life has it is central theme. Each has a task which differentiates it from the other stages of life. Young adults have the task of differentiating themselves from the family of origin. They also do this by attempting to find a mate if they so choose. The young married couple must create their own system, beginning with solidifying their own dyad. The family with young children must adjust to the parenting role, and submerge to some degree their own narcissism. The family with adolescents must increase flexibility and weather the upheaval of adolescent drives and development without the family disintegrating. And the family in the process of launching children must encourage at best and refrain from obstructing at worst their child's emancipation. The parental constellation must also deal with their own issues which are brought on by the "empty nest syndrome".

The task which the family faces in later life is the "life review". This is not to say that there are not other important issues within this phase of life. Life review symbolizes the positive tasks and activity of the period. Butler (1989) says in reference to life review and old age that:

> The summation of one's life work is useful. The consequences of these steps include expiation of guilt, exorcism of problematic childhood identifications, the resolution of intrapsychic conflicts, the reconciliation of family relationships, the transmission of knowledge and values to those who follow, and the renewal of the

ideals of citizenship.

Once the person has entered middle age and their mortality (Cohler, 1982; Jaques, 1965; Jung, 1933; Munnichs, 1966) becomes a reality, there is a shift from the pursuit of external goals and gratification to what Neugarten (1973,1979) calls Interiority. There is a change in the understanding of oneself and one's position in the life cycle.

For the parent in this phase of the life cycle, this new psychological activity of focusing inward may lead to a significant shift in their interpersonal relationships and in relationships to cultural institutions, (Erikson, 1968). Their source of life satisfaction may also change and become less evident to others.

The shift from outer to inner preoccupation is welcomed by the individual but may be misunderstood by the family unit or society at large. Behavior corresponding to the natural internal preoccupation may be perceived as depression, social withdrawal, isolation, and crankiness etc.. This is not necessarily so.

Being alone and the drastic reduction of social contacts may be perceived by the younger generation as undesirable. However, younger people are less tolerant of this form of existence than the elderly. In many cases reduction in social intercourse is desirable, and should not be confused with loss of social supports. Elderly people are much more economical with their time and contacts than other people.

With life review there is a shift from looking to the future and achieving things for the sake of achieving them to an increase in reminiscence. The reduction in strength and physical capacity assists in the shift from achieving to repairing and contributing. There is often a desire to settle old accounts before death; there is a need to look at one's accomplishment: and grade one's life. It is indeed a time when there is an internal battle between "Integrity vs. Despair" (Erikson, 1982). The results of that internal struggle will then be determined by the proper use of Wisdom (Erikson, 1982) which should have already been available to the individual.

With the onset of the last two stages of this particular life cycle schema, the family as a unit is slowly condensed into the issues of the individual. The dyad, if one still exists, still has its issues but they seem less dynamic than the internal process of the individual. This is especially true if the elderly individuals are in relatively good physical health.

Though every question on the questionnaire used in this study is pertinent to the life review, like the other two life cycle stages, specific questions were composed to insure that the issue of life review is addressed.

The issue of life review was very much present in just about every respondent in this category. If they were not planning for their child's welfare in a concrete manner, they were looking at how life has been for them and what they endured and accomplished.

There was a wide range in the variety and intensity of the answers given by the respondents to many of the questions. To begin the life review process, one father chose to focus on his family of origin when asked about how his family got along with each other. He remembers how his family of origin dealt with problems:

> With my family we just explained things different things. My mother had 16 of us. Ten girls. I had one sister living, my mother and father is gone passed and all the sisters passed except one. She's in marry, where is she... In Rochester New York. We talk she calls me.

Another parent, a mother reminisced about her lost love, her husband:

> Well we got along nicely. The last time I went to see him (in the hospital) before he passed away he said baby honey you look tired get into the bed here with me rest yourself (she laughed). I said you know I cant.... It's kind of hard to hold his head... he had a stroke he died from a stroke.

Some memories and review were not pleasant. Some were of failures and disappointments. This mother sacrificed her marriage for her children:

> Well at the beginning of the marriage I had lots of hope. But I didn't see them materialize. I mean there were times when we got along my husband. At the middle of the marriage I sort of seem to think things were crumbling. My husband used to say to me if our boys ever go wrong and give us any trouble out they're going. It was the beginning of Peter's illness and the end of the marriage. We had to separate because it was not good for the children it was not good for him or me.

Her choice was to take care of her two children who had become symptomatic with schizophrenia instead of holding onto her dreams of a perfect marriage and family life. She realized very early in her marriage that her dream would never materialize.

Other unfulfilled hopes and dreams were expressed by this mother as she looks at her life:

> I have a feeling that I have not accomplished much in

> life. My dreams that I had as a girl .... I have not gotten any where in life. Instead of getting anywhere in life I think I've fallen down. I'm at a level, the same level for many years now. I haven't had the strength to go up or down anything I would like to but Ali being there with me now I see another hinderance that's always popping up. It's always on my children and this creates allot of anger within me because the father has never tried to help.

There is pride and a sense of accomplishment among some parents. A mother talks about her husband and their life before they became parents. With pride she says:

> Oh yes indeed, we were both in the service when we meet. Oh yea! The service offers quite a bit. I was in one of the first divisions of the WAC's and my husband (with pride in her voice) was a regular infantry man. Yea he was a regular man.

One father waxed philosophical and offered his views which are difficult to understand. He talks about having lived a full life for which he has no regrets. He offers this wisdom and says in the form of the following statements:

> I have a stupid philosophy in life. It is better to die and live than to die wanting.

The most poignant statements about this issue were made by a single mother who was profiled in a previous chapter. Nearby the entire interview illustrates the mind set and issues of this stage of life. More importantly, there was nothing peculiar, eccentric, or senile about this woman. She was an intelligent, thoughtful, articulate person who retained most of her faculties.

During the interview she made one brief comment which was simple and direct, but the sincerity, the craving and the pain of not being allowed to have such a simple thing such as time alone to reflect, clearly came through.

The thin and temporary euphoria of having a companion quickly evaporated and she realized she and her husband were not a good match. He was abusive and inflexible, and after a great deal of hardship she decided to separate. She abandoned many of her hopes with that action:

> I wanted to have children. My pregnancy was an accident. I was separated from my husband for one year when I found out I was pregnant. Then I got sick and everybody was talking go back to my husband because of the child.

When asked...<u>At what point in your marriage did you feel most satisfaction with yourself, your marriage, and your family?</u> In essence I was looking for indicators and periods of marital satisfaction. She then posed a question:

> In my marriage, I should think all over or just sex life?

she asked.

I then said "all over" and she responded:

> I really for a while when I was working and so I was not completely satisfied with my marriage that's for sure. But I felt so about when I worked I felt I can manage everything. My marriage was one of what kept me all the time down.

She talked about her early days of motherhood and the early experiences of her son, Fred. She recalls one incident which set the stage for how her son was going to react to stressors for a great deal of his life. She says as a child:

> He was all the time very nervous very shy. The first thing I am sorry to say but now I almost can say, good doctors made him me trouble. You see I did not know that the pediatrician the house doctor was so nice but he started to give him the injections. And that's funny, Fred never heard harsh word or anything till he was very content. He was a normal child. Then the first injection the doctor spanked him so he doesn't pay

> attention to the injection. Al began to scream, then no man could come in room that Fred was in. He would yell his head off. And then later when I talked to other people I changed the doctor. No man could go into Fred's room except my husband. A woman can but no man.

I suppose a case may be made for early trauma in the etiology of the illness, but such a case would be very weak.

As the patient grew and navigated through puberty and adolescence, the mother began to have hopes and expectations. She had always been at ease sharing her history and her thoughts with me, and this interview was no exception. She offered parts of her philosophy on flexibility, independence, and how independent she felt her son was going to be. And how he in, fact, turned out to be:

> I expected that he would finish school whatever he would study I was not interested that he would do this or that but that he would be interested in it himself and he would be responsible, nice human being that's all.
>
> I was expecting him to be totally independent. I thought that he would finish school about twenty five or so. I thought I would help him finish college and then he would be on his own.

These expectations were reasonable. After all she believed that an independent person was someone who should be:

> ...able to do for oneself, care for oneself, and be able to function without much assistance from other people. Not to burden anybody else.

Earlier on in the patients young adulthood, she even expected to be a grandmother some day:

> Yes I would like to be and I would like for Alfred it would him give some how such a because it's different when you it's experience one natural wish and second you learn many things it's very valuable experience in life as such because you learn to deal with your deeper emotions and every thing.

When faced with the reality of her son's dysfunction she tried her best to respond to the situation. The issue of flexibility was raised and she responded by saying:

> I am flexible
>
> I guess I am the same. Because I feel so I want leave the other people and try to understand them like they are and not change them, every body is different.

She realized that her son was not functioning at the full level of his potential. She felt pained at the turmoil in his life and the psychological abuse he experienced from his father. For several years he was symptomatic with delusional thinking, alcohol abuse, and unbridled anger. The patient intensely disliked his father because of the emotional abuse his mother had to endure from his father. He often fought with his father and wished him dead.

Unfortunately, his father died following a confrontation between them. The patient became delusional and very guilt-ridden as a result of this incident. He proceeded to shut many of his emotions down especially anger. He no longer outwardly expresses anger. In fact he claims he no longer feels anger. Instead, he feels a wide range of debilitating anxiety and paranoid delusions, including the belief that the government is after him to punish him. He became withdrawn, developed a variety of symptoms including self-mutilating behavior (He would cut himself on his back and chest with a razor).

After his father's death his mother developed a chronic and potentially fatal heart disease. This became another major stressor for Fred. His mother responded to her son's situation by saying:

> I understand him very good but he always think different, he thinks that I should not be worried about him so much about his sickness and every thing. He cannot understand I sometimes I don't know if that's true but I sometimes think that he cannot understand that I worry about him. You see you have children you know, but he has none he cannot imagine how parents or mother can be worried about child, no matter how big he is and old.

Despite his severe symptoms this mother continued to have hope for her son. She looked forward to the day when and if he could resume a normal life:

> Every thing that I would like he would meet somebody and maybe when he marry maybe he would feel that he is belong to somebody right now he is all by himself only me to attach to.

I asked her if the presence of schizophrenia had any effect on her ability to solve the problems of the family. She said "yes". The limitations and financial burden were strongly felt. She said:

> I would not have the problems I have now. For example when he could not be ill I would have my savings I could and even no telling the truth I would manage easy on my own social security and union pension but two people not enough, but I (by myself) I could manage.

The burden she feels comes not only from the financial drain of the causes, but also the never-ending demands of responding to her son's psychiatric needs, symptoms and emergencies. She has to respond to his bouts with anxiety, his suicidal ideation, his frequent hospitalizations and the other situations his condition create.

She is burdened my her inability to voluntarily exit from the situation if she wished. When asked had she ever thought of when her parenting responsibilities would end. With a sardonic laugh, she replied:

> Never ha, ha, ha, ha, . (Do you think it should end?) Yes, if he would be get independent and so even than I at least me I always would be there when he need. I cannot so like I see some people just throw out them in the street and they don't care what happens to them.

The possibility of forcing the patient to live elsewhere is not acceptable at this time simply because he does not have the level of functioning required for such a feat.

Finally this mother tells of her individual needs, feelings and concerns about her situation at this stage in her life:

> I guess we are too close because that's in I guess its time when its not because I don't like him or don't I don't 1 love or what but it's times when I want my some privacy sometime. Its not in bad way and so for him its not good all time watching me getting older or feeble.

At this age she is no longer looking forward to outward gratification. There is very little she desires and there is almost nothing material she wants for herself:

> No there is nothing more for me. (How about going back to Latvia?) No there is nothing anymore for me I wish they would get their independence but my near relatives my father mother sister and two brothers is dead. Last year the oldest brother died last year so nothing the others I never saw him. I saw some but its done that's my home land I wish them all good but its nothing there. Here I don't I expect it could get better with Fred. I started painting. I for second time in my life. I took once paid and every thing number of that famous painting school course but then I figured out it's too expensive.

In preparation for her death she thinks about who will tolerate his symptoms and care for him.

> I worry very much about his welfare when I die.
>
> Right now so far the only thing that, if he at least, if

> he had like you say about that apartment. If he would have place to stay he have every thing whole house or he will stay with me and he don't need at least that to bother because every thing is there that's why I say he has always place to stay.

Simply stated; she is grateful that she has an apartment to leave him.

CHAPTER SUMMARY:

This chapter presented the data about the last stage of the life cycle and the cumulative effect of schizophrenia on that process. The decline in social supports and the increased value of family members in particular a mate of another successful and healthy offspring.

Life review was a prominent task among the parents. Its significance to the emotional well being of the parents and subsequently the entire family was made clear.

SECTION SUMMARY:

This section covered the three stages of the life cycle as outlined by Carter and McGoldricks' (The Family With Adolescents, Launching Children And Moving On, The Family In Later Life). It also reported on the subjects relationship with specific (flexibility, adaptability, burden and onset) variables which are known to be part of the chronic illness syndrome and schizophrenia in particular.

The section was divided into four chapters. The first chapter focussed on the outstanding variables presented in the data that are not part of a life cycle stage per se. The other three chapters covered each of the three life cycle stages.

The findings in the first section suggested that the family with a schizophrenic member responded to the onset and subsequent chronicity of schizophrenia much like families do with other chronic illnesses as reported by the literature. The difference in the family with a schizophrenic member appears to be the confusion and slow adaptation caused by a lack of information about the desease with which they were dealing.

Adaptation and flexibility were effected by the availability and use of social supports.

The findings for the Family With Adolescents section suggest that the parents and families of schizophrenic adolescents experienced a wide range of stressors and subsequent emotions. They were blessed by the fact that they were relatively young and energetic. Their lack of experience with the condition served as both strength and handicap to their attempt to return their mentally ill children to normal functioning.

These parents gave no indication that the presence of schizophrenia effected their negotiation of life cycle tasks. Neither parent was fully addressing all of Carter and McGoldrick's tasks at the time of the interview. However, that seemed more a consequence of other factors in their lives such as their martial circumstances than the patient's condition.

This is not to say that they were not stressed by the illness. It simply seems to imply that the stresses of the illness were not as yet fully integrated into the family system as yet.

The presence of other healthy children will also serve the parents currently in stage IV if the history of this entire sample is consistent. Most of the early onset parents in the subsequent stages were able to achieve mid-life satisfaction through means different from the general population. Because of the unrelenting demands of the illness, they could not afford the luxury of self examination and scrutinization which goes along with achieving certain successes at their age; the threat of the empty nest which looms ahead and other factors which may precipitate of the life stage. They were too busy and their energies spent in dealing with their adolescent, schizophrenic child.

Having a mate seemed to make a significant difference in the parents' ability to utilize a variety of problem solving resources. Single parents did not utilize supports as regularly as intact

couples did; the reason is open to debate. However, it seems that having a mate with whom to share the burden of illness is a-built in resource to the entire family in managing this problem and facilitating movement through the life cycle.

A number of interesting responses were given in the section on Launching Children And Moving On is the longest of the three in terms of years. Many of the normal life cycle issues were being dealt with by the parents and family members in that stage. However, the issues which needed to be negotiated were not necessarily negotiated in the normal sequence, nor were the results very similar to the non symptomatic population. Parents were still able to develop a sense of self and marital satisfaction simply from being exhausted and surviving the extended onset period of the illness. If they were fortunate enough to have other non-symptomatic children, the success of those children were savored went a long way to bolster the parents' self-esteem.

The notion that the parents needed the patient to be symptomatic as espoused by several family systems theoreticians was challenged as a wider picture of the situation was painted.

It appears that burden felt by the parents throughout the life cycle is tremendous and unwanted. The parents were very clear about the amount of dependency they needed from their children. Even those who would be considered enmeshed with their child had a concept of independence for the child which freed the parent of the burden of dealing with schizophrenia. If a desire for enmeshment exists, schizophrenia seem to play very little if any part in the enmeshment of those families.

The value of a supportive person became clear. The notion that social support works better than the individual support resource was also substantiated.

It appears that the final stage of the life cycle is as full and complicated as those which preceded it. The presence and burden of schizophrenia clearly effected certain tasks such as Support Central Role of The Middle Generation, while having virtually no effect on others such as Dealing With The Loss of Spouse or Life Review.

Many parents were concerned with the state of their schizophrenic child. Many who were concerned about this also indicated that they felt they did the best they could and hope the patient will be able to manage when the parent dies.

Once again it was clear that the presence and availability of a support system seem to be extremely useful to the parents. However, the availability appears to be as important if not more important that the actual use. For many parents supports were not utilized in the same manner as they were with the other three stages in the study. These parents seem to value their privacy and independence and resist becoming a burden to their children even the healthy children. Those were not fortunate enough to have a great deal of privacy during the earlier stages of the life cycle appeared to value it as though they were very familiar with it.

The need to pass the baton on to the next generation was clearly an area of major concern and stress for the parents.

Because the schizophrenic offspring is now at the age when that transition should be taking place but are not capable of accepting the responsibility, many parents were saddened and forced to continue that role while attempting to respond to their other developmental needs.

As a group these parents appeared to have become more realistic and pragmatic about their situation. They demonstrated a flexibility which contributes to a low Expressed Emotion (Brown, Birly, Wing, 1962) environment which is good for the patient.

Life review took place whether or not they wanted it to. Many parents seem to resist looking at their lives and evaluating it. Even when they were complaining about a current behavior or situation that were engaged in life review. The force to complete this task was greater that their denial and or conscious or unconscious resistance to take stock of what has been.

The life reviews performed by the parents took a variety of forms. The results were largely curative and reassuring to the parents. Many, especially those with other healthy offsprings appreciated the fact that they survived and accomplished a great deal despite the presence of schizophrenia in their family. Even though burden was present in most cases, guilt for the most part continued to be denied and unobserved.

PROJECT SUMMARY, CONCLUSION, POLICY IMPLICATION, PROGRAM DEVELOPMENT AND TREATMENT IMPLICATIONS

This study was an exploratory in nature, no specific hypothesis was being tested. Instead, a number of questions about families of schizophrenic children were raised.

Observations pointed to a gap in the current literature regarding the specific effect of schizophrenia on the family's ability to negotiate life cycle tasks. Utilizing current knowledge about both of these areas, a clinician may do what he or she does with other clinical issues: surmise, speculate, project, guess, ignore, etc.

There is an absence of specific information and the realization that our theories are limited in offering guiding principles which tell us if we are going north when we need to go north. They can point to the correct street, road or path, and often that's quite enough. However, when the terrain is not well-understood as in the case of the patient's level of vulnerability, and the footing is unpredictable and unsure, as with the severity any psychotic episode, it seems dangerous and costly to continue without a map of the life cycle topography.

There were specific questions to ask as I began the investigation. As the project progressed more questions were generated. (These questions are partially the purpose of this investigation).

In addition to the first question which prompted this investigation, several other questions were asked. Those questions included; What allows some families and parents in particular to appear to have successfully negotiated many life cycle tasks? What prevents those who do not appear to have negotiated the appropriate tasks from accomplishing those tasks?

Among those who were successful, what allowed them to be successful? Among those who appeared not to be keeping up, why not? How do these families and parents in particular realize and identify these life cycle issues? Do they see these apparently middle class issues and are they relevant to all classes?

Also asked was, what happens to these families as they are faced with the developmental tasks of the life cycle? When do they master these tasks, and what resources do they employ in succeeding? Finally, how do they feel about their situation and themselves as individuals, parents, and family members?

One of the most striking findings of this investigation is the diversity among the parents and their responses to the phenomenon of schizophrenia in one of their children.

There were parents who clearly fit the double binding/schizophrenogenic mother/oral fixation concepts (Fromm Reichmann, 1952; Arieti, 1955; Lidz, et al., 1965) and profile. There were also parents who seemed perfectly normal.

It is clear however that all families regardless of their level of health or pathology, felt burdened by the presence of the illness. They all felt managing the illness was a major disruption in their lives and they all felt a significant loss and frustration as a result of the illness.

Clearly some families used the patient's condition to avoid or mask certain limitations of the family system or themselves.

However, even among those individuals of whom there were not many, the sense of burden was palpable, understandable and powerful.

The burden of the illness impinged on their independence and/or their sense of independence. And they all seemed to realize consciously of pre-consciously that flexibility was a basic requirement in achieving and successfully negotiating many of the life cycle and developmental tasks they were asked about.

A surprisingly large number of parents could be rated as having mastered many of their life cycle tasks. However, many did not, and the Epigenetic Theory which posits that success in a set of lower level tasks must be achieved before success in the next higher level can be realized, seems to hold. Nonetheless, the families who were lagging behind did not seem permanently and hopelessly stuck in a lower or earlier stage. There was ample evidence that they kept on striving to achieve independence and more autonomy among all family members. Their difficulties were not in their motivation or hidden agendas only. Their difficulties were in their lack of supports and know how.

It also seemed that the know how is achieved through a process which is similar to the Epigenetic theory of Wynne. That process is interfered with by the stresses of dealing with schizophrenia. It seems to be a permanent phenomenon unlike other chronic illnesses. The stress of dealing with schizophrenia is unrelenting and basically different from most other chronic illness. Based on these parents' experiences, it is different because it does not kill; parents generally know when the next episode will occur.

They are frequently teased with hopes and expectations that he or she will "*snap out of it*" or benefit from a host of other variables.

Those families which could be considered enmeshed and have a schizophrogenetic mother, seem very uncomfortable with the schizophrenic situation. This becomes clear in moving from the earlier stage to the last stage in the life cycle. It seems that at some point, regardless of how pathological the parent was, by the time they reached the final stage of the life cycle, the realities of their mortality forced them to consider the interest of their child as well as to deal with certain life cycle issues such as life review.

This is not to say that every parent or family constellation addressed this issue with the same clarity, motivation, vigor or insight. Nor do the data suggest that the degree of movement toward dealing with life cycle issues is the same for everyone.

Another striking finding involves the value of a mate. When there was a mate the parent felt less burdened and more able to deal with difficult issues. The presence of a mate seems to insulate the family and the other parent against some of the stresses of the illness.

POLICY IMPLICATIONS, PROGRAM DEVELOPMENT AND TREATMENT IMPLICATIONS

Alfred J. Kahn wrote, "Planning is a developmental process in which the levels of intellectual undertaking are in constant interaction.... Although a logical sequence may be listed, it is not necessarily a temporal one. Even as we organize for planning, we must provide for the interplay among levels. For our concerns with assuring a planning outcome which gives appropriate weight to all relevant elements implies a readiness to refine and revise the outcome of earlier stages as we move into later ones".

This clearly has not worked for the families and parents of schizophrenics. The policies and program developments for the mentally ill most of whom are schizophrenic since deinstitutionalization for the most part has ignored most of the families needs. The academic and intellectual have not been any more successful in following this logical and idealistic view of the planning process.

Closer to the reality of meeting the needs of the schizophrenic's caregivers is what Kahn has also espoused; he writes: "In the real world, planning tends to begin because there is complaint, tension, disagreement, dissatisfaction, conflict, suffering, need for choice, a bill enacted by a legislative body with too little foresight, some combination of these or a dream".

Political, social and economic forces gave us the policies of deinstitutionalization. More recently some of these forces have caused the mental health establishment to finally begin recognizing the needs of the family with a schizophrenic member. This study as well as others such as Agnes Hatfiels' (1989) of over 10 years ago which produced a list of services the families of the mentally ill cited as most helpful for themselves in managing their children; may provide a guide for appropriately meeting those needs.

This study also brought additional attention to the complexity of the situation and the need for a comprehensive clinical and policy approach to meeting these needs. It is clear that the caregivers must be seen as complete entities and treated as such.

The discipline best suited for taking the leadership in this area appears to be Social Work. In the mental health field it is the profession whose mandate is exactly what the caregivers are indicating they need, either directly or indirectly.

On the clinical front Social Workers must continue to resist the temptation to reduce the caregivers to a peripheral player with sometimes ominous intentions and behavior towards the patient. They must continue to take advantage of the vast resources and powerful forces that are present in even what appears to be the most difficult and disheartening situation.

Our treatment plans and subsequent interventions must reflect a greater effort to identify the life cycle stages the family, the individuals within and the product of that interface. Successful recognition and respect for these issues can not only facilitate the helping and therapeutic process, but significantly influence policy as well.

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