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UNIVERSITY OF ALBERTA

The Process of Hoping in Families of People With Schizophrenia

by

Daniel S. Scott ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing

Faculty of Nursing

Edmonton, Alberta
Fall, 1994

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Daniel S. Scott

303 Albert Street
Fredericton, New Brunswick
E3B 2B7 Canada

Date: Aug 5/94

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE PROCESS OF HOPING IN FAMILIES OF PEOPLE WITH SCHIZOPHRENIA, submitted by DANIEL SCOTT in partial fulfillment of the requirements of the degree of MASTER OF NURSING.

Dr. Olive Yonge

Dr. Marion Allen

Dr. Ronna Jevne

Date: August 5, 1994

DEDICATION

This thesis is dedicated to Jude Ann Spiers and our love. *Por Tous Jours*.

ABSTRACT

The treatment of schizophrenia has evolved from the 1950s when people were expected to live in institutions. In the 1970s, people were only treated for acute episodes in a hospital. Forty years later, the trend is to provide treatment in the community with the help of the family. The role of mental health nurses has changed, concomitantly an understanding of family strengths is needed. The effects of schizophrenia can be destructive to family structure but there are families that thrive. Hope is known to be a source of strength in similar situations but has not previously been studied in families of people with schizophrenia. The techniques of grounded theory were used in this descriptive study to identify a process of hoping. Incident sampling interviews were done with two hopeful families over a three month period. The process that emerged can be compared to walking a tightrope. The families found themselves at a great height on a narrow rope. They know that there is *something wrong* but schizophrenia defies clear explanation. The first response is *reaching out* for something solid to hold on to. *Reaching out* is often a way to connect with inner resources with the help of others. *Becoming realistic* is an acknowledgment and acceptance of the limits of what can be done. The next category is a reflexive *balancing*. There is a burden of negative consequences of the illness that threatens to unbalance the family unless counter weighed by seeking positives in the situation. *Valuing* is a reflective appreciation of that which is within reach. When the family is *in perspective*, they see their experience as a profound opportunity for personal growth. Implications of this study were identified in the areas of nursing research, education, practice, and administration. Perhaps the most important implication is to change how these families are viewed by nurses. Their extraordinary strengths are identified rather than the usual focus on problems.

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I: Introduction

Schizophrenia

Schizophrenia has been described as the "cancer of psychiatry" (Green, 1984). One in every hundred people worldwide from all cultures and socioeconomic groups will have the disease to some degree (The Schizophrenia Society of Alberta, 1993). About half of those diagnosed with schizophrenia in Canada will not achieve good recovery (Bland, 1984). *The Edmonton Journal* (1993) reported that schizophrenia is estimated to cost Canadians about $4 Billion a year due to health care and lost productivity.

The American Schizophrenia Society describes schizophrenia as a purely physical disorder. This group distributes literature related to orthomolecular treatment and lobbies against the use of any psychiatric or "psychosociological" approaches (Murray & Huelskoetter, 1991). The Schizophrenia Society of Alberta publicizes the disease as a biochemical disorder but does not reject other directions of investigation, as the biological basis of schizophrenia has yet to be determined. Numerous studies suggest a relationship with temporal lobe disease. However, the response to neuroleptic medication indicates that the temporal lobe damage is not the cause but is a consequence of some other process (Merriam, Medalia & Wyszynski, 1993). Viral theories of etiology have support but no virus has been found. Genetic factors are known to be involved but the role and mode of transmission are not understood (Gottesman & Shields, 1984). People with schizophrenia have up to six times more D4 (dopamine) receptors and the most recent medications are effective because they reduce this activity. A dysfunction of a network involving many systems and parts of the brain rather than a malfunction in any single region may eventually provide an explanation (Merriam, Medalia, & Wyszynski, 1993).

The diagnosis of schizophrenia covers many different types of conditions and each of those conditions has symptoms that are found in many other types of illnesses. The diagnostic process is lengthy, often tentative, and extremely frustrating to families seeking definite answers. The DSM-III-R, a diagnostic tool developed by the American Psychiatric Association (1991), includes the definition of schizophrenia as a group of disorders involving severe disorganization of functioning with certain characteristic disturbances of thinking, feeling, and behavior. Each subgroup has different genetic factors, prognosis, and responses to treatment. The subgroups, based on predominant clinical features, are catatonic type, disorganized type, undifferentiated type, paranoid type, and residual type. A person is not considered to have chronic schizophrenia until the time from the first psychotic episode is more than two years.

Schizophrenia and the family

The first psychotic episodes are commonly identified in the teens or early 20s for men and a few years later for women. As a consequence, parents are faced with providing support for many more years than is usually expected. The family is often relied on for support because the person with schizophrenia typically has few friends, poor education, and impaired work performance despite normal or high intelligence (Neligh, 1990). In fact, the family and the person with schizophrenia are sometimes seen as 'inseparable treatment entities'. The family may experience severe grieving due to the loss of a productive future for the ill person, feelings of guilt, depletion of family resources, stigma, and severe realignment of family structure (Baker, 1989).

The episodic, highly variable, and unpredictable course of the illness imposes a severe strain on the family attempting to cope with an ill member. The family never knows what strange, intrusive, or even dangerous situation may occur next. Typically, the psychotic episodes last for weeks or months and are separated by months or years during which the person may be withdrawn, isolated, and behaving oddly. The clinical features of the illness may include thought disruption, delusions, hallucinations, affective disturbance, lack of goals, social withdrawal, and impaired motor activity. After many years of the illness they may be unable to experience pleasure, have few psychotic episodes, are socially withdrawn, and have a permanently flat affect (Tomb, 1988). The families of people with schizophrenia who choose to be actively supportive are engaged in a struggle of heroic proportions.

The role of the family continues to evolve as hospital budgets are cut, social attitudes change, and the pervasive move towards treatment in the community continues. The trend towards deinstitutionalization began in the early 1950s and over the following twenty years hospital beds were reduced by half (Bland, 1984). Although hospitals were no longer seen as a place for people with schizophrenia to live their lives, there was still an expectation that acute problems should be treated in a protected environment. People with schizophrenia frequently lived in a cycle of repeated admissions. This began to change in the 1970s. It was then that the Community Living Project was developed in Madison, Wisconsin, and has since been reproduced in a variety of settings around the world. The Madison Model is now considered the most promising for providing direction in psychiatry. The original research on the model conducted by Stein and Test (1980) was a controlled study of the effect of a 14 month community treatment program on 62 randomly selected people seeking admission for any mental illness except organic brain syndrome or alcoholism. People, even with acute conditions, had a better response to treatment in their own environment than in the hospital's protected environment. The findings have been replicated in several countries and are changing the practice of psychiatry. In hospitals where variations of the Madison Model are used, many people who recently would have been admitted are now sent home to be cared for by their families.

The family and hope

In my nursing practice, I work with families of people with schizophrenia. The standard nursing approaches include counseling, problem solving, and teaching. In my own life, there have been periods of turmoil when a sense of hopefulness continued to be with me after my expectations had collapsed. I was not able to articulate the nature of hope but was aware of it being there when I needed it. I felt the topic was profoundly important but could find no literature about hoping in families of people with schizophrenia. These families have suffered a severe collapse of expectations. In much of the mental health literature, there is an implicit assumption that wellness is achieved through coping and most nursing interventions focus on skills. From my own experience, I doubted that wellness could be understood in terms of doing activities of living effectively. Development of my thoughts on this topic can be attributed to two important influences. In Edmonton, Alberta, there is a Hope Foundation through which many types of exploration related to hoping are supported. I have attended meetings at the Hope House with researchers from a variety of disciplines. The other influence is Parse's nursing theory of Human Becoming. I have attended two conferences on this theory and have read most of the research guided by it.

R. Jevne (personal communication, August 5, 1994), the Program Director of the Hope Foundation, has said that, "hoping is to being, as coping is to doing". Parse's (1987) theory of Human Becoming outlines how being evolves mutually with the environment. Being involves cocreating personal health by choosing meanings in situations. The meanings are personal values reflecting hopes. In other words, our choice of meanings reflects our hopes and cocreates our health with the environment. Wellness is related to what we hope, not what we can cope with.

This investigation of the hoping suggests how some families are able to endure and even thrive in difficult circumstances where hopelessness could be expected. Hopelessness is well described in the literature but hope is rarely mentioned. The purpose of this study was to identify and describe the process of hoping in some families of people with schizophrenia. Hopeful families may or may not be representative. An assumption is being made that even if hopeful families are rare exceptions, they have an experience worth studying.

Research question

The primary research question addressed in this study was: *What is the process of hoping in hopeful families of people with schizophrenia?*

II: Literature Review

The family

The family is a social group characterized by privacy, a collective consciousness that is not readily available to nonfamily members. The relationships are intended to be permanent, shared traditions with intense involvement and a collage of individual qualities (Daly, 1992). Family systems theorists go beyond this definition to describe people as elements in a structure of interlocking relationships rather than autonomous psychological entities (Kerr, 1988). Another view of the close family relationship is provided by symbolic interactionism. People continually interpret and make meaning out of experience, mainly through language. Role expectations are used to measure many aspects of interrelationship within the family. The person's social cognitive ability enables anticipation of another person's reactions and adjustment of behavior, thus they are 'role taking'. The person acquires a sense of self worth and competency through the primary relationships of the family (Porter, 1988). The individual can be more fully understood when seen in the context of the individual's family structure.

None of the literature related to hope puts it directly in the context of family structure. Almost all of the nursing research about hope that was reviewed has been done with individuals having cancer, HIV, or physical disability. The focus of available research about families living with a person with schizophrenia is on information needs, therapy, or coping skills. An important exception was Chelsea's (1991) study using hermeneutic methods to identify caring practices in a sample of 21 families of schizophrenic people. The common views of these families as either burdened by the caregiving or that their family affect is a potential risk factor in the prognosis was not found to be an adequate explanation of the data. This study indicates that there are strengths to be found and hope may underlie those strengths.

After 25 years of research, no evidence has been found that families have anything more than a genetic role in the etiology of schizophrenia. Some therapists continue to treat families as causal agents solely on the basis of speculation (Thornton & Seeman, 1993). Families often wish for a more definite biological explanation to help divert criticism that they are somehow a 'bad' family, an additional burden on coping with a heavily stigmatized illness (Schizophrenia Society of Alberta, 1993; Main, Gerace, & Camilleri, 1993). Currently, the only form of therapy that implies the family has some role in causation is a variation of family systems theory. Schizophrenia is not regarded as a biological defect (although defects may have some role in the manifestations) but is an outcome of a biologically rooted process with many participants and occurring over multiple generations (Kerr, 1988). Some family systems theorists claim that there is schizophrenia in all of us and we all act in ways that contribute to the development of schizophrenia in others. The family is considered just one of many groups we belong to that function in ways to promote the functioning of some and make participation difficult for others (Kerr, 1988).

The role of families in the relapse of the person with schizophrenia is disputed but there is evidence that the family does have an influence. Family interventions aimed at reducing the amount of expressed emotion and increasing cognitive behavioral skills have had the most success as measured by relapse rates. The research has mainly been done by comparing the effects of families with high levels of expressed emotion (EE) with families having low levels. Gamble (1993) combined results from replicated studies and demonstrated that 92% of patients in high EE families relapsed over a nine month period compared with 12% in low EE families. On the basis of these results, interventions to reduce EE in families were advocated. However, it should be noted that the high EE group was not receiving regular medication which may have made the results more dramatic. The article by Gamble included a table which indicated that the high EE group with less than 35 hours family contact and regular medication had a relapse rate of 15%, which is a difference of only 3% from the low EE families. Numerous types of interventions to improve family psychodynamics and educational sessions have had little success. Individual psychotherapy for the person with schizophrenia has been found ineffective and is rarely offered (Schwartz, Cecil, & Iqbal, 1993).

Obtaining a medical diagnosis of schizophrenia has an important effect on the family perceptions. The recognition of schizophrenia as a diagnosis was reported by siblings as a pivotal, reorganizing event that redefined behavior previously viewed as difficult or different (Main, Gerace & Camilleri, 1993). Three studies report that obtaining information about the illness is a major problem for families (Rose, 1983; Main, Gerace & Camilleri, 1993; Gaskill & Cooney, 1992). They felt isolated from hospital staff, the information provided was scarce and confusing, and their experience of the problems was not acknowledged. What they did know experientially was often devalued by professionals. Tennant (1993) reviewed a sample of nursing literature over the past 40 years and found the role of the family to be generally de-emphasized in mental health nursing but well covered in other nursing specialties. One nursing textbook in the review even recommended strategies for excluding the family, although being pleasant to them was advised since they can be quarrelsome.

Wilk (1988) used the Family Environment Scale with 93 family caregivers of people with chronic mental illness to compare quality of life when the person lived at home or away from home. They found a greater amount of commitment, help, and support where the ill person lived at home. The other two dimensions of the scale, personal growth and system maintenance, showed no significant differences. Another study using Maslow's framework found that physical, social, and emotional abuse were serious concerns in families living with a mentally ill person. The older the caregiver and the longer the schizophrenic person was ill were the variables with the most negative impact on quality of life for the family (Seymour & Dawson, 1986). An important difference between these two studies was that the first looked at people who had not been institutionalized and the second looked at those who had been deinstitutionalized.

Two qualitative studies found that *being normal* was an important goal for both the family and the ill person. Robinson (1993) used the constant comparative technique to analyze interviews with 40 people living with a chronic illness or with someone who has a chronic illness. These people did not have schizophrenia. The belief stated in the analysis was that people first make meaning of their lives and then act upon that construction. People structured their experience into stories through a selective process of pruning experience that did not fit. The story of life as 'normal' was commonly preferred by all those in this study. Lorencz (1991) did a grounded theory study of people with schizophrenia preparing for discharge from hospital. A core explanatory variable was *becoming ordinary*. All informants described themselves as failures or *not making it* in the community prior to admission. *Becoming ordinary* meant being normal, productive, community members and the term was used to describe past experience as well as the anticipated future.

The losses due to schizophrenia are ambiguous and pervasive throughout the family social structure. The following statement outlines the difficulties faced by this family member, and many other families of people with schizophrenia (National Schizophrenia Fellowship, 1975, cited in Atkinson, 1986).

> Perhaps only those who have faced it in their own households can fully grasp what it can mean, the problems of managing the unmanageable, of coping with the inexplicable alterations between a known and loved person and an apparent stranger, the headaches over money and the sufferer's maintenance, the nagging anxieties over the long term outcome. Nor are they problems that can be faced, dealt with, finished with. They may drag on for years. Finally, since the disease commonly strikes people in their teens and twenties, parents can be well on in life, with correspondingly reduced resilience and capacity to cope. (p.77)

Passion for the possible

Hope is a word that is deeply rooted in language with a wealth of meaning. An ancient English proverb claims that one should "hope for the best, but prepare for the worst". Kierkegaard's description of hope as "the passion for the possible" recognized hope as a way to summon resources to endure the otherwise unendurable (Godfrey, 1987). Shakespeare expressed a belief that has not lost meaning even in the midst of medical technology, "The miserable have no other medicine/ But only hope". The oldest account of hope is the Greek myth of Pandora, the beautiful mischief (Baird, 1989). She opened the forbidden box, thus letting loose all the evils of the world and by the time the box could be closed only hope remained inside. Hope seems to be considered an evil in this myth but without a harmful effect. In Renaissance art, hope is personified and carrying weapons of death that have been broken (Baird, 1989). A split image also exists in the metaphors collected about hope. Davies (1979) found that all the sayings could be sorted into self canceling pairs such as, "hope never comes- hope never leaves us wretched". Averill, Catlin & Chon (1990) grouped over 300 metaphors into seven abstract categories and found similar contradictions within each. Examples in the category of hope as a form of support include, "hope is a rope" and "hope is grasping at straws". A metaphor, such as "hope is a good breakfast but a bad supper", includes the mixed view of hope.

Some insight into why hope has such mixed descriptions was suggested by the research of Dufault & Martocchino (1985). Two different spheres of hope were identified by observing 92 adults with terminal iliness over a period of two years. The spheres were described as generalized and particularized. Generalized hope provides the climate for developing particular hopes and may rescue the person when those particular hopes fail. One could speculate that hope may often be 'grasping at straws' when it is a particular wish. The sayings that 'hope springs eternal' and 'hope is a rope' refer to the generalized sphere.

R. Jevne (personal communication, August 5, 1994) stated that there are at least two levels of hope. In the first level are the specific hopes that are goals or desires. This level may be similar to particularized hopes. The second level has not yet been fully described. It has been referred to as the "hoping self" and goes beyond the concept of generalized hope. It is a self with a developmental history. For example, one can have hopes about a career or a marriage but the core of these hopes is in the development of the hoping self over the lifetime.

The realities of hope

Various psychological studies indicate that well adjusted people with no distress maintain illusions based on unrealistically positive self evaluation, exaggerated perceptions of self control, and unrealistic optimism about the future (Taylor & Brown, 1988; Bates & Stevens, 1989). Two psychiatrists even described using interventions that aroused feelings of hopelessness in order to obtain realistic perceptions of change and causality (Bennett & Bennett, 1984). Nursing articles have often contained warnings about particularized hope when it is not based in reality (Dubree & Vogelpohl, 1980; McGee, 1984; Duncan & Rodney, 1978). The assumption is made that having unrealistic desires will lead to a poor prognosis and achievable desires will encourage recovery. Yates (1993) discussed how this view is often based on a reality only perceived by the nurse. Patients and families have their own reality within a social context and experience that is very different. It is their reality that is the source of hope, not the goals and limits perceived by the nurse. Weisman (1979) wrote how goals are not central to hope:

> When hopeful people acquire cancer, they are tenacious and resourceful. Therefore, hope is not simply a wish to undo what cannot be changed, nor does it evaporate at bad news. Hopeful people, strangely enough, do not depend as much on goals as upon self-concept, even though self concept is nourished by success in reaching goals...(p. 13).

In contrast to Weisman, Snyder (1993) wrote that hope is only the cognitive perception that goals can be met. This definition was developed into a model of hope as, "a cognitive set that is based on a reciprocally derived sense of successful (a) agency (goal directed determination) and (b) pathways (planning of ways to meet goals)" (Snyder, p.274, 1993). In this model, simply having optimism would be dysfunctional if there is an inadequate pathway. However, a person with 'high hopes' might be able to generate new pathways when the original pathway is blocked. Snyder has assumed there is a general agreement that hope is an overall perception that goals can be met and that hope is a known to be a cognitive phenomenon. The diversity of the literature reviewed does not indicate any consensus that supports these assumptions.

The perspective on reality shared by some nurses may be limited due to the dominance of the desire to cure (Jevne, 1990). Conversations of hospital staff about hopefulness were analyzed to identify how medical mastery is extended into an area dominated by nature and death by simple verbal devices that reduce disruption and challenge (Perakyla, 1991). For example, in curative hope the patient is "getting better" while in palliative hope the patient is "feeling better". When the patient is not getting better or feeling better, the patient is described as "past recovery" and "beyond hope". All variants are linked to maintaining the legitimacy of medicine and not the hope of the patient. In Hall's (1990) study of 11 men with HIV, hope was found to be as important in the last hour of life as in any other time. The medical model was often found to be used to deem hopes as denial or false reality instead of recognizing them as a universal human need.

A variety of definitions of hope from everyday language, poetry, philosophy, psychology, sociology, medicine, and theology are found in the nursing literature (Farran, Wilken & Popovich, 1992). The word is used as a noun or a verb. The verb often refers to a desire to do and the noun is likely to mean there is a chance of a positive outcome but neither usage is without countless exceptions (Godfrey, 1987). The meaning of hope may only be known within the reality of the person using the word. Furthermore, the symbolic richness of the meaning may not be consciously known by that person. Nursing literature tends to deal with conscious and observable components of hope that are related to specific desires but overlooks the hoping self. Jevne (1993) stated that philosophy, in contrast, has examined the nature of this hoping self extensively. For example, Frankl concluded that hope is a spirituality without a religious context or an undiscovered part of the unconscious (Dufrane & Leclair, 1984). Schrag (1977) argued that hope is not on the level of concepts but situated at the level of symbols and images.

Fravel and Boss (1992) conducted an in-depth interview with the parents of three boys who had been missing since 1951. They had expected that extended hope after such an ambiguous loss would be dysfunctional. However, the parents had spent the years since 1951 in hope but not in any disarray. The researchers described this finding as a challenge to their own "pathologizing perspective" and speculated that the parents may not be in disarray because they had been hoping. The parents were realistic about the chances of ever finding their sons, but giving up hope was unthinkable for them. There is an old saying that "hope is a poor guide but good company". These parents had found hope to be good company without assuming that their hopes had to be the sole guide to dealing with the loss.

The nature of hope

Dufault and Marocchino (1985) found no specific passion or affective state that could be identified as the feeling of hope. Feelings of uncertainty, uneasiness, fear, and captivity are commonly present but hope is considered an antidote to them (Averill, Catlin & Chon, 1990; Jevne, 1993; Miller, 1991). When Averill, Catlin and Chon (1990) questioned 150 undergraduate students about hope as an emotion they were told that hope was difficult to control, affects thinking, can lead you to act in inappropriate ways, motivates behavior, and is a universal experience. Other studies and concept analyses describe hope as an energized state (Haase, et. al. 1992; Hall, 1990; Owen, 1989; Stephenson, 1991). People with hope had more energy for living and for acting towards positive outcomes in their future.

The 150 students questioned by Averill, Catlin and Chon (1990) described hope as experientially less real than other passions such as love or anger because it was difficult to point to an action. They shared a social norm that if one has hope, one should work harder towards goals. All of the literature reviewed indicated that hope was action oriented. One case example described a patient who made no effort to help himself but expressed hope that he would get better anyhow. The authors used him to illustrate false hope (Dubree & Vogelpohl, 1980). The nursing literature describes a nursing role in maintaining, supporting, and restoring hope but the focus is often on aspects that can be reduced to behavioral objectives (Jevne, 1993). Hope is seen as something leading to helpful activity but helpful activity does not necessarily lead to hope.

A common theme among the definitions of hope is that of connectedness (Jevne, 1993; Haase, et al., 1992; Zimmerman, 1990; Dufault & Martocchino, 1985; Brown, 1977). An involvement beyond the self, mutual communication of caring, and sustaining strength through a community of people are identified as the primary means of developing hope. Stories, rituals, images, humor, and symbolic activities have been used to help move together towards the potential of hope (Jevne, 1993). Hope has a future orientation that is rooted in the past and experienced in the present with others (Dufault & Martocchino, 1985; Miller, 1991). Nurses are often in a position to be with others when sharing hope is needed.

III: The Research Method

Grounded theory techniques

The techniques of grounded theory were used in this descriptive study. Families share numerous meanings that are often contradictory or hidden. This study used a qualitative research framework to accommodate multiple perspectives and see the family as a unit (Daly, 1992). When little is known about a subject, qualitative methods are appropriate ways to inductively derive categories and frameworks from the data (Field & Morse, 1985). Hoping is a process that occurs in interaction with significant other people and evolves over time. Both of these attributes are matched by a grounded theory approach to family groups. The grounded theory method can be used to generate substantive theory in a horizontal relationship with a rich matrix of meaning rather than hypotheses testing and deduction from general principles (Gilgun, 1992). Development of theoretically informed interpretations is not only a powerful way to bring reality to light but theories are the most systematic way to build, synthesize, and integrate scientific knowledge (Strauss & Corbin, 1990).

It is indicated in some literature that the depth of hope is beyond the reach of consciousness. Hope is a profound experience and no claim can be made to have captured its depth with the grounded theory method. This study is limited to what is articulated about the effect of hoping within the shared family perspective. Furthermore, families and all other social groups have knowledge that is not revealed to outsiders and some aspects of hoping will not be divulged. While acknowledging these limits, the method is considered an effective match for the diversity of family forms and experiences (Daly, 1992).

Incident sampling

Informants met the minimum criteria of having been involved directly in caregiving for a person with a diagnosis of schizophrenia for more than two years (chronic). they were over the age of 18 years, articulate about their experience, and able to describe themselves as hopeful. Two families were interviewed and both had experience of providing support for at least seven years. The first family interviewed, with pseudonyms of Betty and Jim, were parents of two people with schizophrenia. The second family, with pseudonyms of Jane and Bill, had one son with the illness. Mary is the pseudonym of a grandmother in the second family. Both families included other children who were not interviewed. All participants are currently employed in jobs related to health care. The definition of 'family' used in this study was a group of significantly related people with diverse membership, social roles, common culture, and boundaries that separate insiders from outsiders (Daly, 1992). The focus of this study was the family and not the person with schizophrenia. Both families were supporting members who had been diagnosed with schizophrenia in their childhood.

Sampling on the basis of concepts that have theoretical relevance to the evolving theory was used. Strauss and Corbin (1990) state that concepts have theoretical relevance when they are repeatedly present, notably absent, or have become categories through coding procedures. In research using grounded theory techniques, incidents are sampled, not people (Strauss & Corbin, 1990). Over time, the interview questions became more focused on incidents related to the emerging analysis.

Access procedures

Families tend to have one member who acts as a 'gatekeeper' (Daly, 1992). Both families were accessed through a member who made all the necessary arrangements. These families were contacted with the assistance of the Schizophrenia Society of Alberta. During initial discussions with family members, the intent of the research was explicitly described and they were aware that interviews were focused on what the family has experienced in relation to hoping. Both families requested and were given a complete copy of the research proposal prior to the first interview and all indicated they had read it. The families were informed of their right to withdraw at any time from the research.

Data collection

Individual interviews were used to initially discover personal perspectives. Following this, all participating members of the family were interviewed together, as outlined in appendix B. The interviews were done in a three month period. The first family had been interviewed individually and together before the second family had been contacted. The selection of both families was purposeful.

The group interview was an important source of information on how varied personal perspectives were related together in the family. Particular attention was given to the nature of verbal and nonverbal interaction around hope related themes. This interaction is often the actual process-in-action rather than second hand telling about the process (Swanson, 1986). Observations of family interactions were collected in field notes by Dr. O. Yonge for one family and by Pauline Belanger, an MN Candidate, for the other family. The use of both individual and group interviews was another source of validity through data triangulation.

It is indicated in the literature that hope may have two spheres that each require different approaches. Particular hopes may be accessible through direct questions about what is desired. Generalized hoping may be understood through the symbolism and imagery of stories. Interviews were conducted with sensitivity to these two spheres. The initial interviews explored a prepared range of topics (see appendix C) but further questioning was dependent on issues that emerge during the research process. Prior to the first interview, the researcher was interviewed by another graduate student to identify personal bias and perspective. During the interview, I discussed how I was approaching the first interviews with little understanding of how these families could remain intact and thriving.

I could work well with people suffering from schizophrenia but did not know how I would handle living with them. I have not had that type of experience.

Data analysis

Coding, conceptualization, and categorizing was done as the data was collected and used to determine the direction of future data collection. The techniques of enhancing theoretical sensitivity enabled the researcher to perform these procedures in a way that used experience and knowledge to open the data rather than to obscure it (Strauss & Corbin, 1990). These techniques included imagining the opposite of what was observed, analysis of single words or phrases, making comparisons with the similar and very dissimilar, and looking closer at what was assumed. Triangulation of sources from individual and family interviews was another procedure to enhance the richness of data.

In qualitative research the researcher is the instrument. The quality of the data and the depth of the analysis are dependent on the ability of the researcher (Field & Morse, 1985). As a novice researcher, I needed to validate my interview techniques and sensitivity of data analysis with my supervisor through regularly scheduled meetings. Effective validation relies on meticulous documentation and reporting of research activities. Only through self awareness of mind-set can the researcher begin to explore and understand another's world (Hutchinson, 1986). As part of my effort to increase self awareness, I attended a workshop entitled *Exploring Your Hope* at the Hope Foundation. I also attended monthly meetings of researchers in the area of hope at the Hope House. I work as a staff nurse in a hospital based program that provides support to people with schizophrenia and their families in their homes. This role allows frequent opportunities to be with families providing support to a person with schizophrenia. Based on that experience, I was able to appreciate the depth and comprehensive scope of the data provided by the study participants.

The purpose of analysis is to code the data into useful categories and to develop a filing system with procedures for retrieval of data (Field & Morse, 1985). The method of coding described by Strauss and Corbin (1990) was followed. In their approach, open coding was used to "fracture" the data and allow categories properties and dimensions to be identified. Axial coding was a technique used to put the data back together by making connections between a category and its subcategories. The focus of axial coding was on specifying a category in terms of the conditions causing it to occur; the context; the strategies by which it is carried out; and the consequences of those strategies. Selective coding was used to integrate the categories to form a grounded theory. This integration was not much different than axial coding but was done at a higher level of analysis.

The filing system used during this coding process was initially the ProFile® software developed for qualitative analysis on Macintosh® computers. Two transcripts were coded and entered into this system. However, as the analysis progressed, a simpler system of covering a wall with pieces of paper was found to be more suited to my style of work. The pieces of paper were excerpts from transcripts, notes, and various levels of labels. It looked crude but allowed one to ponder and sort large amounts of data visually rather than manipulating the software to retrieve small bits of data. There are advantages to both approaches but I could think more clearly in front of a cluttered wall than a screen with a list of code words.

Trustworthiness

Sandelowski (1993) described validation as a culturally and historically situated social process. Trustworthiness is a matter of persuasion by making practices visible. Reality is multiple, constructed, and there is no consensus on its nature. Awareness of personal construction of reality related to this study was an issue that was explored prior to data collection (Strauss & Corbin, 1990). A taped interview of myself was done by an MN student to discover what my perspective might be. In my experience as a nurse working with families of people with schizophrenia, I frequently see the difficulties faced by those supporting of someone with schizophrenia. People with this mental illness usually do not feel comfortable being around others and can easily misinterpret even the most well intentioned attempt to provide help. They have a strong tendency towards social isolation, which often allows fears and distortions of reality to grow. The nature of the illness can defeat both the families' and the nurses' efforts to help. The struggle to provide support is often full of anger, grief, frustration, fear, and despair. I have also seen families that have found ways to live with this illness that go beyond the problems and they have been the inspiration for this study. I understood the severity of the difficulties and wanted to know more about their strengths. Some assumptions that I made prior to the study were that hope exists; there is a process of hoping; families will want to talk about the process; hope is necessary; and there is a evidence of a direction and source of hoping.

In the grounded theory method, the data is from the reality perceived by the participants. This reality was explored through semistructured interviews in which various types of questions, such as open ended and reframed, were used. The participants were all interviewed at least twice. By interviewing individually and then with other family members present, the personal view could be identified and then discussed in the family context. My role as a nurse in the community was helpful since I work directly with people in similar circumstances as the participants. I could verify that the participants views were comprehensive and fit well with the reality of others. The first transcript and coding was reviewed by my thesis supervisor and feedback provided. Several meetings were held with my supervisor and MN students currently engaged in research to discuss data collection, analysis, and related issues. Two interviews were observed and written feedback about the interview process was obtained. One interview was observed by my thesis supervisor and the other by an experienced mental health nurse. The family agreed to have the nurse to observe instead of the thesis supervisor. Having a different person observe provided an additional perspective on the interview process. The entire collection of transcripts, coding, and analysis materials were critiqued at two points late in the research process by an MN prepared nurse who has published grounded theory research. I also attended monthly meetings at the Hope House with other researchers in the area of hope and became familiar with issues specifically related to that topic. An audit trail of recorded tapes and notes exists. The data collection schedule is in Appendix B. My preferred approach was to observe any research related activity and make notes at a later time of the salient information.

Two group presentations were done and extensive feedback received. The first presentation was to nurses in the Department of Psychiatry at the University of Alberta Hospital. Various issues related to my research proposal and hope were discussed. The second presentation was to members of the Schizophrenia Society of Alberta. The emerging process was presented to families and their responses were recorded in notes.

Ethical considerations

Hope is a sensitive topic that can evoke intense emotional responses and touch on personal information that is of an essentially private nature. Cowles (1988) wrote that obtaining informed consent, promising anonymity, and even offering counseling resources may not be enough. There must also be consideration of timing, the participant's and researcher's response to sensitive topics, and how sensitive material is handled with trust. Hope is a human need and is vulnerable to the clumsy trampling of 'objective' feet. Kvale (1988) pointed out that a qualitative research interview and a therapeutic interview may both involve increased understanding and change. The difference is in the emphasis on intellectual understanding in the research interview and on personal change in the therapeutic interview. Although the research interview may have entered areas where therapy could be useful, the researcher did not take a therapeutic role. The participants described themselves as comfortable with discussing these issues and did not require additional therapeutic intervention.

The informed consent form had a Flesch-Kincaid Grade Level of 8, which is sufficient for the purposes of this study. The form (see Appendix A) covered the usual ethical requirements of anonymity, right to withdraw, voluntary participation, protection from harm, and to be informed. Ethical clearance was obtained from the University of Alberta and the University of Alberta Hospitals. Letters of support were provided by Dr. Bland, the Chair of Psychiatry, at the University of Alberta Hospitals and the Schizophrenia Society of Alberta (Edmonton Chapter).

To ensure anonymity, only code numbers were linked to the data. Names and locations in quotations have been replaced with an **X** or **Y**. All names used are pseudonyms. The author is identified by an **I**. The tapes do not have identifying data erased but this material is deleted in the transcripts. Consent forms are stored separately from the data in a locked cabinet and will be kept for five years. Tapes, disks, and notes are stored in a locked space and will be destroyed or erased seven years after completion of the study.

IV: Findings

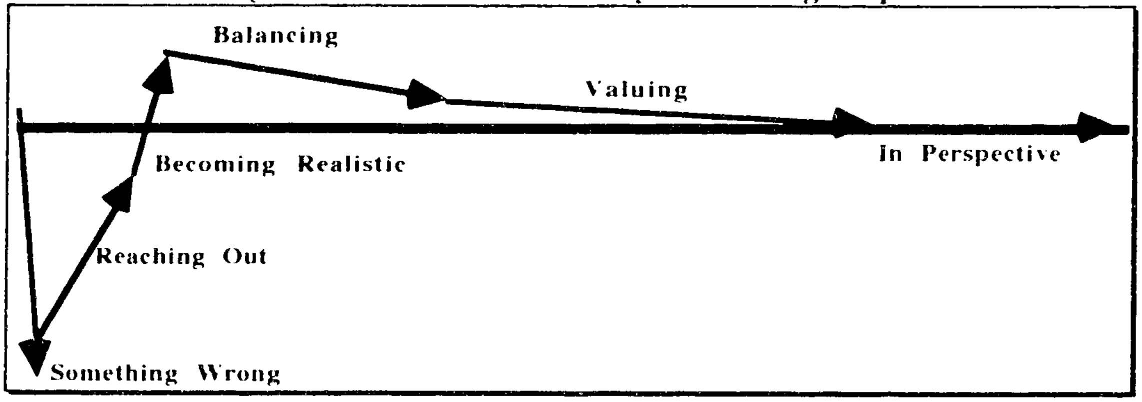
Overview

Before presenting the analysis, a brief overview will provide a sense of the process that emerged. The core variable was identified as *Walking the Tightrope*. The choice of this metaphor brought together elements of high risk, skills that improve with experience, a point of view from a height, and the courage to make a commitment. In Biblical Hebrew, the most common word used for 'hope' is 'tikvah' which has the root meaning of 'cord' (M'Clintock & Strong, 1970). One of the primary meanings in *The New Shorter Oxford Dictionary* (1993) of 'cord' is that it is a rope composed of several strands twisted together. When the family is *walking the tightrope*, the hoping process is not described by the walking and may be more related to the metaphorical rope that keeps them suspended safely. In other words, what the families may be *doing* is learning to live with the consequences of schizophrenia. Hoping is related to their *being*, the nature of their existence. At the beginning of the process, this difference may not be as obvious as it is in the later stages. When someone fears falling, the potential opportunities of the situation are not the priority. With experience, the fear of falling diminishes and there is a shift in attention. One way to identify the hoping process is in terms of the source, direction, or object of hoping, and the evidence given by the participants for their hoping. These factors will be outlined in the discussions of findings.

The families who participated in this study did not choose to walk their tightrope but found themselves there. They described this experience as a "drastic awakening" or in terms of "knowing something was wrong". As the person begins walking, the theme of *reaching out* predominated. Hope was related to wanting something solid to grasp, partly a reaction to the uncertainties of walking the tightrope. *Becoming realistic* was the acknowledgment of the limits of what can be reached and hoping was described as within the limits of what could be done. *Balancing* was a way of finding positives to weigh against the negatives. Sometimes that meant hoping that someday in the future medical researchers would find a cure or that today the family would enjoy the comics from the newspaper together. If all the weight went to the "bad", then one could fall into the "quagmire". Closely related to *balancing* is *valuing* what is within reach rather than what one might have valued under other circumstances. There may be a hope that society also realizes the value those with a mental illness. *In perspective* was the stage where the view from the tightrope was accepted and seen as an opportunity.

There is a folk saying that "hope is a poor guide but good company". One participant said that even when depressed to the point of attempting suicide, hope was always there in the background. When the participants were faced with walking a narrow tightrope at a great height they often could not afford to look down. In the early stages, their center of gravity was often unbalanced, as shown in Figure IV- 1. At all times hope was a way of bringing their attention to something more positive, to steady themselves, and giving them the will to continue. The following figure shows the potential for losing balance, but it is important to point out that this is not the hoping process. It is the part of the context in which hoping occurs.

Figure IV- 1: **Center of Gravity on the Tightrope**



I began this study with almost no idea of what I might find. As interviews were done and transcribed, I cut them into segments as part of the coding process. The tightrope metaphor occurred to me while reading the transcripts and sensing the emotions. When the coding was sorted according to the metaphor, it seemed to be like window cleaning. The process was simply obscured and only needed to be washed. *The New Shorter Oxford Dictionary* (1993) includes a definition of hope as having a trust or a confidence. Family members also talked about coping and it is often not clearly separated from hoping. To cope is defined as dealing competently with one's life or situation. Walking on a narrow rope certainly requires the ability to walk, but it also requires a sense of trust or confidence.

People on ladders, rooftops, and other heights are often told- "Don't look down". In some ways, hopelessness is like looking down. At the hospital where I work, patients in the community treatment program are often assessed with the Beck Hopelessness Scale to determine their level of risk for suicide or self harm. While thinking about the tightrope metaphor, I wondered how many nursing approaches have the effect of drawing attention to the possibility of a fall rather than the potentials of the situation.

Walking together

The uncertainty of an episodic illness and the frequent inability of the ill person to make appropriate decisions help create the context of the walk. One participant stated that the ill person requires a very specific set of conditions to be happy but is unable to create those conditions without extensive help from the family and others. The family is metaphorically steadying the person with the illness across the tightrope. Steadying is not the same in the parental relationship with children who do not have schizophrenia. The person with schizophrenia acts like someone with severe vertigo- unable to balance and often clutching at others desperately.

> **Jane: ...in the beginning, definitely it was us on the rope. ...I don't know where he was on the rope or he was probably the one pulling us off is what it was. But not now.**
>
> **I think it switched for me when I saw myself not as being a mother so much as almost a caregiver or a social worker or something like that. And when I see myself in that role it's more of a supporting role. Like he's not yanking me off it anymore or himself or if I'm on it he's not trying to off balance me that I end it. Maybe that's what the thing is now.**

> **He's on it and I'm trying to keep him so he's not falling off whether it's the rope or life or whatever it is.**

Steadying involves knowing the patterns of the person with schizophrenia and preparing for times when there is likely to be a fall.

> **Mary: By doing stuff like giving him, arranging for the right school and giving him these things and sort of, he's falling here. Where's he going to fall? Here's the school, sort of balance him back up and he needs something over here. And try and balance that.**

The hopes are often related to this fragility of the circumstance that allows a person with schizophrenia to find happiness. Almost anything has the potential to create turmoil.

> **Mary: So that has to, he has to be helped, circumstances have to made for him to have that without his being able to analyze and deciding what is required...**
>
> **My hopes are exactly that those circumstances are able to be brought together and that nothing will rip them asunder. You know how tenuous some of this is. So that nothing will rip them asunder and that he will be, that he will be sufficiently protected so that he can be happy with himself and feel that he can hold his head up. And that he is at peace, that he's not in constant turmoil with himself.**

An assumption in the choice to interview families as individuals and as groups was that the burden was being shared differently among the family members. The differences were part of a growing process as the family learns to deal with a relentlessly difficult situation.

> **Betty: You just need a way to be able to deal with it, I think if both people have that, that's a lot better, but that's not necessarily going to happen. I think two people meeting a situation can be quite variable in how their response is going to be. And to support one another is terribly difficult at first. So, yeah, there's hope in growing with it. And maybe understanding how to cope with it more.**

Differences in how family members walked at any specific point in time were found to be related to timing and parental role. Although the different roles were apparent in individual interviews, in the group interviews a family story was visible. Notes taken during the group interviews indicated that these families were skilled at interacting with each other for a common purpose.

Timing refers to how caregivers compensate for each other in the rhythms of daily living. There is an understanding that while it is not humanly possible for one person to always be ready to deal with every situation, others are there to help. One participant said, "It wears on, and it's difficult to rise to it appropriately all the time".

> **Jim: In a way it changes you, you know, I guess you just don't know from day to day. You live it from day to day is really what, the way it is. You just, and X is great because, you know, you all have your days when you're up or down. Hopefully when you're down somebody else is up. And vice versa.**

Differences related to parental role were more complex. Both families reported a distinct difference in mother and father role. The illness commonly affects males at a younger age than females. All of the participants were caregivers for young boys with schizophrenia and the mothering role seemed critical. A father said, "The kids do come to the mothers in a special way, then (mothers are) burdened more with it". The mother role may be more related to the nature of the illness rather than common beliefs about mothering. The participant quoted in the following excerpt saw her son as often simply "clinging" due to his needs. She saw herself more as working for him than being a mother to him.

> **Jane: Part of his illness, his identity is enmeshed with mine, which is part of the illness. Which, when he was living in our home was very, very frustrating. If I cut my finger then that, or if I got ill or whatever it just meant that his life was over. It was just horrible. OK, so and he doesn't have the same way of thinking with his father or his brother and sister. It just, it's not the same. I could say, you know daddy's you know, broken his right toe or, oh yeah. It means nothing. I'm very guarded to tell him that I'm even have a serious cold or he even starts worrying about that if he hears me on the phone. And I really play it down. I could be on death's door but he just can't handle it.**

One father said the difference in roles sometimes led to misunderstanding of the family dynamics by outsiders. Because the son would respond differently to him, others might assume that he was somehow doing something wrong as a parent.

> **Bill: Yeah, and still a little bit of maybe just of hearing what everybody else was saying all the time well you shouldn't you**

> **know, you've done something wrong. You've done this or it's all your fault because he only reacts when you say that to him. Why don't you be more understanding of him or why don't you do this or you know, change your behavior. But it's really easy to say and it's really hard to do...like if he was dealing with X he would do this. And if he was dealing with me he would do this.**

The impact on a couple's relationship was a severe "shock" which both families overcame. Some of the reasons given for the survival of the relationships were their maturity, a period of building a relationship before having to cope with the illness, and previous experience with medical problems. All had training and substantial experience in the health care field which may have contributed to a sense of the illness as something to be controlled and coped with, rather than just a bizarre aberration.

> **Jim: I think one of the things that I'm finding is that I'm glad this happened, I was going to say, in the forty to fifty and fifty to sixty age group for us. I think there's a little bit more tolerance and calmness in some ways that we wouldn't have had if this had happened when we were in our twenties. I don't think that we would have handled it as well. We've had to shoulder a few ups and downs throughout our marriage that I guess in some way gave us a little bit more sticking strength when this shock came along.**

It is possible that the hoping process would be different when the parents are inexperienced adults in their early twenties but maybe they would be "drawing on the same sort of thing".

> **Betty: ...if you're a newly married couple you'd be dealing with some of these things that'd be very devastating to your marriage, I think. More so than later when you have got the groundwork laid for a good relationship. And I think there is quite a difference. I know in talking to others that are burdened with the condition it seems that it's a different problem at different ages. So I think if a person has experienced a few things it's going to be easier to carry that burden. Yeah, I think there's a hope in, and that the hope changes. But maybe you're drawing on the same sort of thing.**

Walking the tightrope was done as a family group and was not an individual endeavor. The differences in ways of walking were related to roles and timing within the family group more than individual characteristics. The person with schizophrenia was considered a member of the group and extraordinary efforts were made to keep the person on the rope. All of the people with schizophrenia in this study were diagnosed during childhood. There may be a different process in families that have a member become ill in a later developmental stage when separation from the primary family is expected. On the other hand, the families may also be "drawing on the same sort of thing".

Tightropes and reality

After preliminary analysis of five transcripts had been completed, I presented the emerging process to a meeting of about thirty members of the Schizophrenia Society of Alberta (Edmonton). A lively discussion ensued. One woman said that the process fit her experience very well and she recognized her hoping as described in each phase. She stated that in the beginning she had not been able to imagine reaching the point of *in perspective* but it describes where she is now.

Most of the other comments were directed at the relation of hope and reality. For example, a man told a story of two golfers who wanted to play better. One golfer took lessons and the other hoped to be a better golfer. Today, the golfer who took lessons is the better golfer. Another woman argued that her son relies on unrealistic expectations or hopes of what he will be in the future and this is just an excuse for not doing his school work in the present. She did not agree that hopes were useful to him. Another man, afterwards, told me that he thinks hope and faith are the same, and he would not have survived without them. He said there were times when he was aware that his hope/faith was all that he had left. He felt the topic was of ultimate importance. Two people wondered whether some are born with a hopeful character or orientation and others are not. Those who do not have a hopeful character/orientation may not have access to hope, even if they know it is useful. One person speculated that hope may be influenced by serotonin levels. There was no consensus about the process of hoping, except that it was an important topic. The views on hope were diverse and there seemed to be a split between those who saw it as wishful thinking (like the golfer without lessons) and those who also saw the potential of a more profound way to view reality (like the man with faith).

The following quote illustrated how one of the participants in this study viewed the issue of hope and reality.

> **Jane: ...if people don't understand my sense of hope they say, well, pie in the sky, get down to reality here. And I'm not, I am a very realistic person. But that's my motivation. That's my internal drive, the hope.**
> **...They've got, they have boundaries. They have a deeper understanding of the limits. When you understand your limits, then, to me, then you are even more hopeful, it gives you, it's not an empty hope. It's a deeper hope. It's more substantial. It's not just words. So, I think of things deeply. And I don't just say, oh, I hope that happens. What are the limitations? What do you need to do to make it happen? It's not just an empty word.**

The view of this participant was in direct contrast to a man in the audience who firmly declared that there is no cure for schizophrenia, therefore no hope. The families that participated in this study were hopeful a satisfactory life could be created within the limits of what they could do. The difference of views on hope could be related to differences in experience. At an earlier point in the process, the participants may have not seen hope as within reach.

Part I: Back Then

This part of the process was consistently described by the participants as being in the past. They were recalling what it was like back then as part of the explanation for how it is now.

> **Jane: ...you've got to understand, even how he is now is different, but *back then*, I mean, he didn't go out and play with kids. He hid in the bushes. He acted very strangely. His thinking was very jumbled.**

Something wrong.

The realization that they were on a tightrope came before the families knew why. There was a lengthy period of observing unusual behaviors and having an intuitive awareness that something was wrong. Both families sought help immediately to identify what was wrong but did not get clear answers. The signs and symptoms of schizophrenia all may appear with other mental disorders. Diagnosis is based on patterns observed over time rather than any one specific event or symptom.

> **Jane: I was the first one to, even when he was a baby, to know something was wrong. I knew something was wrong. I knew on one hand that there was something drastically wrong. I had him to the hospital to be tested for hearing, for speech, for anything I could think of because I didn't know what was going wrong. And my husband and other people were saying boys develop slower than girls, just to calm me down, or I don't see anything. Are you overreacting? Maybe you're a little too sensitive. All of those types of things. And I, and even professionals would do that and say well, we see perhaps some indications but just wait a few years and see what happens in school. And I took the role of shaking people by their shoulders and saying there is something wrong. I said that I'm not waiting. How many years do you want me to wait? There's something wrong now. But looking back I realize there was nothing they could do then. And maybe they realized that too, and just didn't want to say anything more.**

The following participant imagined that the diagnosis will have the impact of a death in the family with which she knows she can cope.

> **Betty: ...I think you can handle whatever you have to if you know what's going on, if you can have a grasp of what the condition is. Whether or not its, I'd sat with a lot of people that have died, many people. And I figured if I can handle things like that emotionally and physically, because it is exhausting mentally and physically on you, that I was certainly capable of handling whatever diagnosis our son may have.**

The variable and episodic nature of the illness had an effect on hopes. The shifting limit of possibilities created a cruel uncertainty. It could be something serious, or maybe it wasn't.

> **Jane: I thought, what, this is worse than mental retardation. I've worked with many people you know, in my former jobs and at least you, it's consistent. You know what you have. You know there's no false pretense, there's no hope changes. Like one day he's better. He seems fine, he seems normal. The next day, it's like where have you gone? So the hope, it's like, oh, this is great and then it hits you in the face. Oh, this is not good. It seemed to come in cycles. And that inconsistency was**

> **worse. Because it was ever changing. One day he would not even know how to spell his name, the next day, you know, everything, he was right on cue with. So it was very, very difficult to figure out what exactly was going on. How much control he had. If he really wanted to, like, couldn't he pull himself together or just do it or whatever.**

In summary, hoping during the period of *something wrong* has a source in previous experiences. The direction is still towards a cure because those with medical expertise are reputed to have cures for diseases.

Reaching out.

In response to finding themselves at a great height, on a narrow tightrope, there was a *reaching out* for something solid to hold on to. The right medical experts, obtaining a diagnosis, other family members, getting away from the situation, and friends all offer some possibility of stability. Nevertheless, this illness was "massive".

> **Jim: Yeah, a person gets a little more realistic, within, at first, well, we have to go through the doctors and cure this problem, problems, and you sort of figure it's a stage of recovery and they're going to do fine. And so you're quite hopeful that these people deal with these matters.**
> **...Well, we could see that you know, people needed help with it. We were not going to be able to handle this ourselves. People are going to have to be able to get away from it. You know, maybe the other son getting away from it will give him a chance to recover. My wife getting away from it will allow her to recover. Because I know their strengths. I know that they can. I mean I have that hope. And, but it's massive. It's overwhelming.**

At the same time, there was a sense that *reaching out* is actually a way of reaching in to inner strengths. The participant acknowledges that human weaknesses can allow a person to lose access to inner strengths. However, others can compensate for those weaknesses and the person can continue to draw on these strengths. Hope was identified as essential to this process.

> **Jim: Yeah, I mean I don't know how others view hope. It's something, that, you have to have it or else you're gone. So you have to draw on something. And, I don't know, I just believe that people have an inner strength. They just need help at times to have it... And we all have our weaknesses and**

> **areas we're vulnerable. But I think everybody has some inner strengths and they can have it beaten right out of them maybe. But I think other people can help with that so that you can continue to draw on it.**

Other family members could be a source of hope because they were perceived to have strength. Even though the actions of the other family members may be suicidal, the belief in their strength could make the participant feel hopeful. When hopeful, there was an ability to draw on one's own strengths, as described in the previous quote.

> **Jim: Well, I drew hope from the strength of my youngest son and my wife. That, when it was really it's worst, then I had hope in their strengths of dealing with it. If once being able to get relief from someone. And yes, it did happen.**
> **...Yes, they were a source of hope for me. Even though, you know, they were suicidal too. So, I still had that hope, their strength, I think the realization of their strength. But I, what else was there going to be. It had to be that I guess.**

Hope was consistently described as obtained through a connection to others. The following two stories are about that connection. In the first story the connection was with a friend and in the second the connection is with a memory of a parent. In both stories the other person seems to represent qualities such as goodness, faithfulness, and caring. The fact that such a person existed, even in memory, was enough to renew faith that there were others who understood, and this experience did not need to be suffered entirely alone.

> **I: ...Is there any thoughts or images that carried you through that you could describe, or what you would describe as related to hope?**
> **Betty: There were a couple of things that were really, really meaningful to me at that time. I became quite suicidal and that's why I ended up in hospital. There was a friend that really stuck by me through this and just seemed to be, I was going to say supportive but it almost seems that word just doesn't quite do it justice. This man is a priest, Anglican priest. And I was feeling guilty that the church was going to say oh, bad, bad, bad. You know, you can't do this on top of everything else that we had. But he didn't do that. He was very supportive to my husband and to my other younger sons. He met with them and checked up on them to make sure that they had somebody to talk to. And he was not our, we did not attend his church. It was a friendship, describes it.**
>
> **I had been fighting a depression for several months and was on medication. My doctor wanted me to increase the**

medication because it wasn't as effective as it should have been. And I had declined to do that because I didn't feel that I had the extra hundred dollars to pay for it. So I said no.

There was a day came when there was a lot of things happened just within a very short period of time. I ended up going to, into our bathroom and just decided I was going to kill myself. I took the knife with me. And my son was standing outside the bathroom door, banging on the door and talking to me and crying and telling me not to do this. So I put the knife down and thought OK, I'll go and see my doctor.

And I went to see her and I couldn't tell her. I mean, to admit that was just too much so I cried and didn't tell her why I was there really. I remember her saying if you want me to phone and get an appointment for you to see a psychiatrist and to try and get you into hospital. And I said no, I think I'll be OK. I can handle all of it.

And I left her office and got down inside of the mall and all of a sudden I realized that I was breaking down. And that I wasn't alright. And I went to a pay phone and tried to phone my husband. I couldn't reach him. I phoned this friend. And I don't know what I must have sounded like but I think whatever it was it must have been pretty scary.

But I remember his voice. I can just hear him stop right in his tracks. I knew exactly the look on his face even though we weren't together. And this man said, oh my God, where are you? And I didn't know where I was. I couldn't tell him. I had no idea by this time what mall I was in or anything. I just knew I was in a mall. But I couldn't think. All I was doing was crying and reacting at that time.

And I remember him saying to me just keep talking to me. I'm going to come. I'm going to be there. I'll be there in ten minutes. I can come and get you. He said can you look around and there must be something that you can see from where you're standing. He said is there a parking lot or is there a restaurant. What can you see? And there was a restaurant. I couldn't read the name. I could sound out the letters for him but I couldn't put the word together. And suddenly he was there. He was there for me.

And he took me home. Phoned my husband and phoned a cousin of mine to come from x. And she came and stayed with me for five days until they could get me into hospital. And I remember, I remember my husband in the background. I don't remember anything. Time was nothing. It was just in hindsight I found out it was five days. But at that time I didn't have any time concept.

Um, I think even at that I felt so much that I had so many things to look forward to that if I could just hang on a little longer I'd get through this. That I would find somebody that would try and understand all the feelings I had and not let me do something stupid like kill myself. Because it was just, it seemed so desperate.

> **This friend was just there for me. I can remember him sitting across the room and it was just his gentleness and his strength and his faith and that he was there for me I guess.**
>
> **...And I think we just had a lot of hope that we'd be able to find someone to start talking to and to work through all the, I don't know what it is, everything. There's anger and there's, you're afraid and you're mad because you try and explain something to people that don't have any idea what you're going through. You feel, I felt that I'd let my husband down, to try and kill yourself it's pretty drastic. But somehow underneath of that there was still a lot of hope that somehow we could get past this. If they could just hang in there and support me a little bit longer. And I was one of the lucky ones. There was some good people.**

Another way of *Reaching Out* was to memories of a childhood experience. This story was related on many levels to Betty's current experience with her friend. It is important to compare the elements of this story with the previous. Both describe an extraordinary presence with whom Betty connected and from whom she drew hope. In both stories the hope was related to the existence of good people. In the first story, good people help her in the present and in the second there is a trust created that help will be available to her children in the future. Both are stories that have power to evoke her faith in the goodness of others. These stories have probably been repeated many times, at least internally, due to their evocative power.

> **Betty: I found a couple of things. One thing was, I thought a lot about my dad. Cause my dad was really, I just admired him so much. He had a hard life and yet he was a very responsible and a very loving person. And we had, he had five children in his family and one of my sisters was hospitalized when she was about sixteen or seventeen maybe, sixteen. I was still only five at the time so I'm not sure, but she was in her mid teens. And all I knew at the time was that they, I remember overhearing one time that they said it was costing more than a thousand dollars to go to the specialists and they didn't have the money. And finally she was removed from our home and taken to a, it's a, oh I forget the name now. x I think they called it or something, it was a rehabilitation center in x. And so they had taken her there.**
>
> **And I just remember my dad being so strong for everybody. I can remember my mother being this tiny little person who was so hurt that she couldn't look after her. My sister, what I remember of her was that she was tall and big boned and it was like looking at somebody that was lying in a**

> hospital bed that was probably physically weak but her body build was about three times that of my mother. And she had epilepsy. At that time she was having forty or fifty seizures a day. And there wasn't any medicines for her. There wasn't anything that they could do. And I remember my father just somehow holding her so gently and didn't stop loving her. Didn't stop giving up.
>
> We would go on Sunday drives and go from our small town down to visit her and take her out for an ice cream cone. And it was, even though she couldn't speak by that time, she didn't have words, she lost her speech over the years, I remember her eyes would just shine with brightness when my dad walked in the room. And if he gave her an ice cream cone she was just so happy. You know, it was like it was OK again. And I think remembering that, I kept thinking it must have been so hard for my mom and dad to have to send one of their children away.
>
> And I sort of wished I could have told them about it or talked to them about it because I might have been able to handle things better. It was very vivid, very vivid memories of that...
>
> But it, I think it just made me very aware that here we were like say thirty or forty years later going through probably something very similar to what my parents must have felt but we didn't see the tears. We didn't see a lot of it. They protected us because we were younger children. But somehow I knew a lot more than most little five or six year olds were because I can remember picking up on a lot of things that were happening.
>
> We didn't go to church. My father was an undertaker and I didn't realize it until years later of course, but he also had a heart condition. And so I remember asking him one time why he, why we didn't go to church. And he said because he went to church five days a week with every family that died. And that because of his asthma and his heart he just didn't feel he could sit indoors, he had to take his day like Sunday and just be at home. And somehow it seemed rather strange that here we are all these years later that we don't go to church anymore. But we still have a lot of faith. We still have a lot of assurance I guess, or comfort that our sons will be looked after if not by us, by someone else...
>
> But somehow I trust that there will be friends or someone that comes that will overlook the illness, that will overlook the, I was going to say the symptoms, that sort of separate them from having a relationship with someone. That somehow there's people out there still that are good people that are going to help out when the time comes that we can't help anymore.

As parents, an important role was being the sort of people that the person with schizophrenia could have faith. Their hope was that *reaching out* will be learned from them.

> **Betty: I hope that they can learn from us that, and I think they have already, I mean we're not going to give up on them. We have bad days. We have days when we're kind of fed up with it all and not sure if we're going to have enough strength to hang in there with them. But we'll never give up. Never give up on them.**

In summary, hoping during this period had a source in the strength of others. The direction of hoping was toward inner strengths. The evidence was experienced with friends and family.

Becoming realistic.

Becoming Realistic does not refer simply to obtaining a medical diagnosis but describes a larger realization that "the problems are here to stay". It is "looking at it in the face" and seeing the enormity of the illness. The early hopes related to the illness are, naturally, that it will go away and that the family will survive the crises. The families survived but the illness did not go away. The desire for it to go away was then identified as "pie in the sky" and only setting themselves up for failure.

> **Jim: Well I guess maybe we see the condition and that they need a big support initially, maybe it'll go away. Maybe there'll be a remission from it, whatever. But the more you talk to people and read and you see that it, that it's a chronic condition.**

Becoming realistic is also more than becoming informed about the illness. The information could be used to delay the realization that the illness would not go away. The following participant had the expectation that they could learn to handle the illness to the extent that the son would eventually "go back to normal". Eventually a new normal based on his limits was hoped for and accepted.

> **Jane: And the more I got educated about schizophrenia and the more resources, I learned how to handle the illness and the behaviors and what to do and the more hopeful I felt that at least a different level of comfort or living ability would be achieved for him. So it improved over the years.**
>
> **Then reality kind of set in. Then I realized that my hope for his future was not going to be as it was before he was**

> **diagnosed. I became very hopeless and then hopeful, almost like in denial or whatever.**
> ***I: OK, so this was hopeful that things would get back to normal.***
> **Jane: Right, absolutely, back to normal. He's going to go on meds. They're going to fix him in the hospital. He was hospitalized several times for long periods. This is great, they finally have a handle on it. He's on medication.**
>
> **Then as the years rolled by I realized well wait a minute, the medication is not curing him. This is what this means in the long term throughout his life. Then reality set in so hope then again changed to a more realistic, it wasn't quite as bleak as in the beginning but it kind of settled in to a 'I hope he can finish school. Period'. I hope that he doesn't have to be on AISH for the rest of his life.**

In the following quote, the reference to "lesser hopes" was changed to "lesser expectations". There was an implicit recognition among the participants that hopes and expectations are different. Reality reduced expectations but the hopes were not diminished.

> **Jim: So... I still hope that they're going to reach some of their potential. But realistically I know the condition seems to come and go and deprive them of many things. So I guess in, you have lesser hopes- lesser expectations maybe is a better word.**

The daily difficulty of living with someone with schizophrenia results in misplaced steps due to the very understandable fatigue. The resulting disruption may again create a need for *reaching out* or any other phase of the process. The process was not simply linear but was like a walk across a rope and subject to winds and poorly chosen steps. Each phase was not finished but participants find skills and perspectives that are added to a repertoire of abilities.

> **Jane: You have to get back on track here. Then I'm OK. So whenever I know I'm getting frustrated, I know that I have forgotten the skills momentarily. So I guess I don't fall off. Yes I still get frustrated but then I'm much, much more quickly, I'm able to, you know, kind of change things around and to do things differently and help him instead of being taken down by him.**

The participants have learned the limits of psychiatry. The medication helps control symptoms but is far from a cure. After the diagnosis, the family is still living with someone suffering profound social difficulties. To many, that prospect might seem unbearable, but the participants found ways to do something with it.

> **Jane: I thought the answer would be in the diagnosis somehow. Then you move beyond that and say, OK the diagnosis is just a label,...a label, a diagnosis is only as good as what you plan to do with it or what it means to you or what you can add to it.**

In summary, the source of hoping in this part of the process was in the acceptance of reality. The direction of hoping was toward the possibilities and the evidence was what they knew could be done.

Discussion.

The following figure IV- 2 outlines the source, direction, and evidence for hoping *back then*. Source refers to where the participants drew their hope. For example, in *reaching out* a friend was a source of hope. In the presence of the friend's faith and strength, hoping moved in the direction of finding inner strengths. The evidence is the descriptions given of the relationships with the friend.

Figure IV- 2: **Hoping: Back Then**

	Something Wrong	**Reaching Out**	**Becoming Realistic**
Source	Previous experience with serious problems	Strength of others	Acceptance of reality
Direction	Hope for cure or that it will go away	Finding inner strengths	Potentials, the possibles
Evidence	Medical expertise can cure	Found in relation to others	Seeing what can be done

When walking the rope was seen as precarious, the hopes tend to be related to staying on the rope. In this part of the process, the participants have become aware that something is overwhelmingly wrong with a family member. *Reaching out* during the initial crises and *becoming realistic* include efforts to lower the center of gravity on the tightrope. By accepting reality or seeing the strength of others, the family was becoming less likely to topple over. This increased stability allows for the next part, when the tightrope will be seen as an opportunity.

Part II: The Opportunity

The participants have reached the point of adding to or doing something with the diagnosis. Although they may forget or slip occasionally, their repertoire of skills was moving them beyond the perceptual confines of the rope.

> **Jane: I think it has really enriched me, not only professionally but personally as well. It has strengthened me. It has been, I felt, at times I felt angry cause I felt it was a personal test. That God was, had shot me with his whatever. But now I think, no, God has offered this *opportunity* to me instead of you know, done something to me is doing something with me. And that is a great source of my hope and my strength.**

Balancing.

The harsh reality of schizophrenia continually threatens to overwhelm. The participants describe ways of finding positives to balance against the negatives. One participant said that sometimes it was an issue of finding something positive or falling in the 'quagmire'.

> **Jim: ...when they're getting psychotic there's no self worth there it seems. They just, they would end their life. Just walk out in the street and let a car run over them or go and overdose on anything that's in the house...**

The satisfying moments are actively sought, savored, and stored in memory for use for when times are not going well. The illness was episodic which means the losses are not consistent over time. The person's functioning can be quite normal one day and in total disarray the next. These changes are not predictable or due to any apparent cause. The family has to be skilled at buffering the turbulence or balance was easily lost. The use of good memories seems to be a primary means of *balancing*.

> **Jim: ...And with the boys you look at their moments, you know. Simple things like they all seem to, you know, I put out the comics first thing in the morning and they all read them. And they all get pleasure out of that. I mean, there's some neat things in there that they get. And I think it helps set the day a little bit. So a simple thing like that I can see and share with the enjoyment that they have with something like that. And**

> **they do have their creative times. Like, you know, for X it's great to see him be able to sit down, play some music, write something to make music about and be hopeful about it.**
>
> **And similarly with the other one, sure he's, he just can't spend very long on a task like he used to be able to. Like his studies. But at least he still has the interest in learning something. ...But to see that he's got sparks of interest in all of those things at times is still encouraging. So you reflect on those moments I guess when they, there's some normalcy there. And actually a high level of thoughts in areas where they might have just been flat. Such a contrast. So I guess you savor the precious moments...**

As one might expect, hopes are often related to the person with schizophrenia finding some meaningful satisfactions, such as the sharing an enjoyment of the comics. The ability of the person to know what has been lost was often a liability. Comparison to others without the illness leads to low self worth and a lack of hope. In the following quote, the reference to medical advances was being used to reassure the person with the illness that there is hope in the future.

> **Jim: ...the kid says well I'd like to play ball today, well, he can't hit the damn ball you know, it seems to go along with it. So when they're up, when they try things you hate to see them failing. But there is still hope that they may find something that will give them some of those satisfactions that they're not able to get from so many other things...**
> *I: Do you feel that they will achieve that sense of self worth?*
> **Jim: I think there are things that they might be able to do a little that can give them that. But they may not believe it at certain times. And that's a real pain in the neck. It's their lack of hope that's so damaging to them. But there are times when they can see things. They're bright and they can see things but the brightness, they also think that they see things that they can't do. Maybe more than others. So that really puts them down.**
> *I: When they compare themselves to others you mean.*
> **Jim: I hear them sort of questioning what their future is. But there's hope. And I think if we keep talking about it with them. You have to have reality about what this illness is and we, you know, I'm optimistic that, well I hear they're doing, people are doing brain mapping. I hear fantastic strides in genetics. I hear them talking about the medications and how we sort of see a change in the effectiveness and the side effects with the medications. So there are improvements there. I see great improvements. Whether or not you'll get a cure coming out of it, not tomorrow sort of thing. But yeah, I'm optimistic that boy, there's a lot of things going on right now.**

> **There's some pretty good hopes that the situation could be improved anyway.**

Hope was found in the moments of joy. These moments are more important than meeting the expectations of others. Their importance lies in the context of being surrounded by a depressing reality. Of course, part of that depressing reality was the inability to meet the expectations of others. The hope in "small things" can provide balance.

> **Jim: It's more important that they have some happiness in their life than all these expectations people might have upon them. Myself included. And if they're not psychotic they can enjoy these things even though they might have a depressing look at themselves and their futures, along with us having similar, myself, having similar feelings.**

The person with the illness was often unable to comprehend the situation and has difficulty learning from past experience. The family was trying to foresee problems and compensate.

> **Bill: ...every time he runs into trouble I say to him you know, next time. I try to build on or use a next time this happens, you know, this is what you can do. But every time is like a new time to him. And he can't build on previous resources and experience.**

Although the person may easily fall, there was still a safety tether linked to the family and they often can "reel him back". The reeling was explicitly described as using "love, control, change of circumstances" or "whatever". Reeling is part of balancing when the counter weights of positives are not enough in a specific situation.

> **Jane: But I often feel it just takes a puff of wind for him to fall. Could meet up with one person that influences him and he's gone.**

The family was becoming skilled at walking the tightrope steadily, or as one participant said, "the rope is becoming wider". This skill was compared to having a "balancing stick".

> **Mary: Well, I'd say that they have discovered a balancing stick to lead them on the tightrope. This is, they just balance better than they used to. Experience, everything else, you know. Understanding the disease, everything has given X and Y the ability to steady themselves a little bit as they walk. Rather than tipping them from side to side.**

In summary, this part of the process has a source in the family member's own reflexive abilities. The direction of hoping was toward living well and the evidence of that possibility was seen in the small joys.

Valuing.

Valuing was realizing the worth of that which is within reach. It was a more reflective than balancing and thus less concerned with the daily activity of walking on the tightrope. *Valuing* has a similar orientation as *balancing* because both involve seeking strengths. The difference was that *balancing* tends to be more reflexive and *valuing* is more reflective. In other words, one balances because it is a necessity but values because the worth is appreciated. Valuing was looking at the 'larger picture'.

The participants were all affected by the low value placed on those with mental illness by society. One participant described seeing her son laughed at on the street. They developed an appreciation for the struggles of those with schizophrenia and valued them as people, not stereotypes. There was a hope that values of society can eventually be changed.

> **Jim: You can't save the world but what I'm saying is that, yeah, people need to know of the condition and need to understand that they're not the crazed characters that you see represented on TV or shows and so on. That they're human beings that need help.**

Both families saw the larger society as full of good people, like themselves, who had not been through the process of living with someone with schizophrenia. The experience was an "intellectual and emotional change" of understanding. They had to focus on what was important to them rather than simply accept the views of others who had not undergone this experience.

> **Mary: ...It's a long struggle. It's not something that's going to happen overnight. I think it's a combination of experience and education and government attitude and even in the schools, attitude that is projected. Words that the teachers use. I just think it's all of society has got to support to make people with mental illnesses as useful as possible to society and to themselves. And I think we're a long way from that. But moving in that general direction, but much too slow.**

> **...And then, you know, who knows maybe years in the future there'll be more acceptance. It'll be kind of like hire-a-student, only you know there'll be that, there might even be incentives. My hope is that it'll be accepted and embraced and there is a, you know, value to having people help instead of all these people with mental illness wandering all over the streets.**

The understanding from their experiences was not limited to those with schizophrenia but included other social problems as well. For example, at one time the conventional view that people on welfare are lazy might have been accepted without questioning. Since then, the lack of understanding in such "public remarks" was seen.

> **Jim: ...And now I have a better understanding of it and problems that I live with day in and out. And it's really significant. So it has enriched my awareness. So it's not all bad I guess. There's good and bad. But I think I'm better able to help somebody than before. What I knew of schizophrenia before, you'd say in a joking way and you know, really inappropriately, when you think of it. And yet I was in a medical area and I talked to people and I knew people in the mental health field. And yet didn't really have a true grasp of what it meant. Just a superficial one.**

Both families are actively involved in changing public values by sharing their own experiences. In the following quote, the need to change was defined as being larger than a lack of resources. The lack of hope people have about the illness was what needed to change. That lack of hope is related to only seeing the problem and not valuing the person.

> **Jane: ...actually it's rather selfish that I hope by every person that I speak to that is in direct contact with my son, like a teacher or the principal or the conferences that I do or whatever, that if they can see the illness in a different light, not to be afraid of it, not to get all hung up on the label... It's not only going to be helping my son but the next person that follows him and the next person after that.**

Within the family there was also a shifting from the conventional values of society to values more appropriate to their situation. A "good life" was being redefined to include that which is within reach.

> ***I: A good life is something that is inside of you.***
> **Jim: Yeah, it's a, having good feelings. Like with the family it's, you know, it was nice when they're all around and you had lots of people and they were interacting and you're**

> **enjoying because of their accomplishments and their interests. Not just their achievements but their excitement to have maybe found something. I mean it's great. But with the two boys it's kind of dashed. But a lesser pleasure is good too. Boy, if they can all just been able to react together and, you know, in a sharing way of whatever they can have....**

The families placed a high value on happiness or peace of mind and soul for the person with schizophrenia. The happiness was based on being satisfied with oneself, even if others looked at your life as being troubled.

> **Jane: I see X as having that peace already now for him, at the level he can have it. Cause I ask him about that often. ...I phrase it, like, are you happy? Are you truly happy and content? And he says yes mom, I am very, very happy. Now it's not my idea of a great time, what he's going through, but for him he couldn't be happier right now. And he's known things to be, I shouldn't say complete, because even so, you know, you can see how troubled he is, but in the overall picture he's happier now than he's ever been in his life.**

In summary, this part of the hoping process had a source in the family member's own reflective abilities. The direction of hoping is toward appreciating the worth of others and the evidence has been found in their own experience with the illness.

In perspective.

The participants certainly would not have wanted the family member to have schizophrenia. It was the rope they had to walk and there is now an appreciation of the opportunities for growth that have emerged from the process. One of the definitions of 'perspective' in *The New Shorter Oxford Dictionary* (p. 2172, 1993) is, "a mental view of the relative importance of the relationships or aspects of a subject or matter". The participants are now at a point where they have a perspective on the process.

The following participant described how he could have been "caught up" in a more shallow lifestyle without having to consider what is really important.

> **Jim: But I could have been maybe going and enjoying the high life a bit more. ...which we can't do because we've got to focus here, I suppose we could get caught up in some of that, which is shallow. But I think down deep you know, that**

> **there's some realization of what's important in feeling for another.**

Hope is related to personal changes as a result of the "struggle". The experience has touched deeply. It has been a "gift" that may not have been hoped for in the earlier phases, but it was full of hope. Hoping has moved from a desire for external changes to a state of hopefulness related to internal growth. The process was not limited by the illness.

> **Jane: I'm not a religious person but I am very, very spiritual and I believe that his schizophrenia has come into my life for a purpose. And that I am to learn from it. It's not about him entirely. It's about what my experience is in all of it. And what I'm supposed to do with it. It's already coming to happen. It's already changed my life for the better.**
>
> **So, there's, if you want hope, there's hope. It went from being really bad to enriching my life. It's been a struggle but I wouldn't have traded it and I don't want to trade it. And I feel fortunate that I guess I've had the opportunity to struggle with it. Because of what I do, how I am personally...**
>
> **I mean, this is a gift that has come to me. You can't read this in a book. There is no, there is no book that is going to share the experience of what touches your heart.**

The following interview excerpt outlines this participant's view of being *in perspective*. After gaining profound experience from dealing with a problem, one can "reframe" it as an opportunity for growth. In the early stages, it does not seem possible that one could be grateful for the problem and people are not likely to understand how it could enrich their life.

> **Jane: I'll relate it parallel to the addictions. When I work with people with an addiction, they go through the, "Why didn't I stop?, What did I do? There's the whole genetic component too. And so there are some similarities and in the beginning they don't see, they're not grateful as AA says. They're not grateful for being an alcoholic. And it really gets them angry when they hear people, "Hi I'm Joe and I'm a grateful alcoholic". What do you mean grateful? This is horrible, this is awful. How can you be grateful?**
>
> **And they haven't reframed it in their mind through this hardship, through this trying time, negative experience, whatever you want to call it, I have come to grow. My life is richer or whatever. Or I was given the opportunity to stop the press, have a look-see at what I'm doing, where I want to go and enrich my life. That comes in later stages of recovery. And**

> **I think that's true also for family struggling with, anybody with mental illness or whatever problem.**

"Putting energy towards hope" can be done by telling others that they can move beyond the "devastation part". Since hope was experienced in connection with others, then one can intentionally have hope by sharing it.

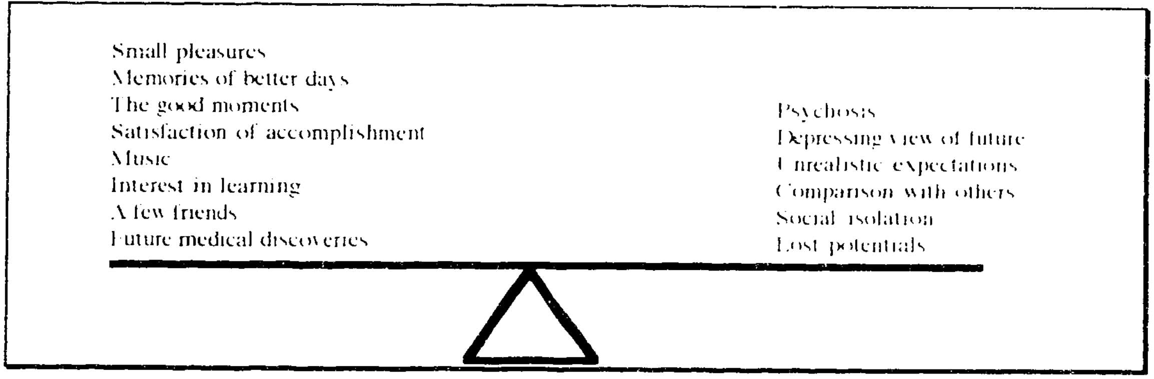
> **Jane: And even as I was going out there and advocating, I was, it was my way of putting the energies towards hope, towards moving beyond the devastation part or going out and letting people know that it's not the end of the world...**

In summary, this final part of the hoping process has a source in lived wisdom. The direction is towards profound growth and the evidence is in their perspective on living.

Discussion.

In section of *the opportunity*, the center of gravity is much lower to the rope and issues move beyond only staying on. *Balancing* was described as a reflexive skill since it is often done automatically. For example, one participant told his son about the remarkable advances of science when he was asked about the future because he had to "keep a level of hope". Figure IV- 3 depicts the balance that was described in the participant's quotes.

Figure IV- 3: **The Balance**



Valuing was reflective and involved a world view that was being changed by the experience with the illness. The families once shared many of the stereotypes of mental illness commonly held by society but now see past the strange behaviors to the essential worth of those with mental illness or other conditions. One participant describes a society where people are afraid of each other unnecessarily because of perceived differences, much like someone looking up at a tightrope may fear it.

In the process of *valuing*, the families are also discovering what is really important to them. In the next step of the process, there is an appreciation of the opportunity to have been able to undergo this experience instead of being "caught up" in usual superficial pursuits. *In perspective* is an earned wisdom. The relationships among the important elements of life are seen.

Figure IV- 4 depicts a summary of the second section of the hoping process. In figure IV- 5, both sections are combined to show how the entire process fits together.

Figure IV- 4: **Hoping: The Opportunity**

	Balancing	**Valuing**	**In Perspective**
Source	Own reflexive ability	Own reflective ability	Lived wisdom
Direction	Living well	Appreciating the worth of others	Profound growth
Evidence	Finding small joys	Experience with the illness	Perspective on living

The source or the ground of hoping refers to where people attribute the origin or where the analysis indicates it may come from. Hope was always experienced in connection with others and figures IV: 3-5 briefly lists the nature of that connection. For example, 'Own reflexive ability' refers to the participant's conscious efforts to keep a level of hope in others by balancing the negatives.

The direction of hoping is toward what is being hoped for. The object of hope may be explicit, such as a 'cure', or implied in actions like 'appreciating the worth of others'. Early in the process, the hopes tend to be for external changes There is a wish for the situation to change, this gradually becomes a new way to see the situation because of internal changes.

The evidence for hoping is what is offered as confirmation or reason to believe. In the beginning, a cure can be hoped for because medical expertise has a reputation for cures. In *valuing*, the experience with the illness has provided insights and views of others that confirm what is being hoped for has substance. By the stage of *in perspective*, there is an awareness of how one's view of the process has deepened over time.

Figure IV- 5: **The Hoping Process**

	Back Then			*The Opportunity*		
HOPE →	**Something Wrong**	**Reaching Out**	**Becoming Realistic**	**Balancing**	**Valuing**	**In Perspective**
Source	Previous experiences	Strength of others	Acceptance of reality	Own reflexive ability	Own reflective ability	Lived wisdom
Direction	Cure	Inner strengths	The possible	Living well	Appreciating the worth of others	Profound growth
Evidence	Medical expertise	Experienced with friends family	What can be done	Finding small joys	Experience with the illness	Perspective on living

The process as I have described is not reducible to a chain of decisions. Other types of process may have linkages where if A occurs, then either options B or C are chosen with subsequent consequences. The hoping process is more suited to a metaphor like a tightrope than a schematic diagram. The process unfolds through increasing awareness of the situation. There are decisions being made but they are best described as commitments. The families were committed to supporting their member with schizophrenia. They could have distanced themselves from the person through various other routes than the tightrope. At any point in the walk, there could have been a loss of will to carry on. They are walking in the context of a society that stigmatizes mental illness and a medical system that is almost blind to anything but the pathology. Such a walk requires a deep commitment. not just an intellectual decision.

In medical science, there has been a tremendous effort to cure schizophrenia. At this point in time, there is no cure in sight and the cause still remains unknown. Medication does help control symptoms but most people with the chronic illness are severely disabled. There is an old prayer in which one asks for the courage to accept what can not be changed, the courage to change what can be changed, and the wisdom to know the difference. This is a fitting description of what the participants have experienced.

V: Implications

This chapter has three sections. In the first section there will be a discussion of some ways to relate the hoping process to the literature reviewed. In the second section there will be an examination of the limitations and strengths of the method. The thesis will conclude with a discussion of some possible directions for further research, education, and administration.

The literature

If the members of a family do not value their life circumstance, there may be high levels of Expressed Emotion (EE). Tension due to harsh, overly critical, attitudes is characteristic of high EE families. The literature refers to high levels of EE in families as being related to a high relapse rate (Gamble, 1993). One can assume that levels of EE would drop considerably as the family works through the process which has been identified in this study. When the situation is seen as an opportunity, the person with schizophrenia is accepted and valued.

Studies of the quality of family life indicated that there were considerable differences between families living with someone who has been deinstitutionalized and someone who has not lived in an institution (Wilk, 1988; Seymour & Dawson, 1986). When the person had been deinstitutionalized, there were serious concerns of physical, social, and emotional abuse. One could speculate that institutional living would have disrupted the growth process of acceptance and valuing by the family. Without interaction with the person with the schizophrenia, one's view of the situation would have no soil in which to grow.

Robinson (1993) used the grounded theory method to analyze interviews with 40 people with chronic illness. It was found that the story of life as 'normal' was commonly preferred and maintained by pruning experience which did not fit. The participants in my study repeatedly mentioned how society needs to change its definition of what is normal but they did not seem to edit their experience to fit current definitions. This approach is consistent with their valuing of what was within reach.

Fravel and Boss (1992) add confirmation that hoping can not only co-exist with a harsh reality often considered hopeless but may be integral to staying healthy. The parents had been hoping for three decades that their sons would be found. The researchers expected that such prolonged hope would be pathological. Instead, they found that the parents had an accurate view of reality and were not in any disarray. The researchers concluded that their hope may be keeping them healthy rather than being a dysfunctional response.

In the study by Averill, Catlin, and Chon (1990) hope was described by the participants as experientially less real because it was difficult to point to a hopeful action. There was also difficulty pointing to a hopeful emotion. Feelings of uncertainty, uneasiness, fear, and captivity were commonly present but hope was a type of antidote to them. In my study there was a persistent difficulty describing the hoping process because there are not specific actions or emotions that are hoping. I could describe the context and indicate the source, direction, and evidence. The quotes of participants referred to hopes. However, the phenomenon remains elusive to exact description. Snyder (1993) reduced hoping to a cognitive activity. This approach seemed to me to be like putting a sandwich in a blender. The results may have elements of the sandwich but it is no longer a sandwich. The symbolic and literary richness of hoping go beyond the limits of an explanation based on cognitive function.

Factors to consider

One of the factors to consider was the sampling. The five participants provided a wealth of data about incidents. They were chosen on the basis of their extensive experience with the research topic. It is believed that sufficient data was collected to generate a description which other families in similar circumstances would recognize as related to their experience. Other types of sampling would add further depth and richness to the study.

Families that describe themselves in terms of hopelessness could provide contrast and insight into hoping. In this study, the siblings were not interviewed and they may have a very different perspective on the hoping process. Living with a person with schizophrenia before one has matured may involve a unique set of difficulties and strengths. Both of the families in my study were living with teenagers with schizophrenia. Interviews of families with adults having schizophrenia may provide different types of incidents to sample. These two families are looking back at previous periods in their lives and may be overly selective of memories. Further study could explore the perceptions of families currently undergoing experiences in each of the categories. These studies would add dimensions and concepts that are obscured by more distant recall. Finally, interviewing the people with schizophrenia may provide an important perspective. People with schizophrenia often have an impaired ability to articulate experience but are capable of profound description. Lorencz (1991) study of the experience of leaving hospital indicates potential in that direction of inquiry.

The techniques of grounded theory were appropriate to the research question in this study. There has been no previous research on this topic. Grounded analysis of interviews are effective to open the door and enter a topic. Future research can explore the contents of the topic with techniques that assume a body of knowledge already exists about the room they are in.

The interviews used incident sampling techniques and this was found to be a productive approach. I did notice that the family group interviews were less revealing and more subdued than the individual interviews. The sequence could be part of the reason for a difference. When individual interviews were done first there was an enthusiasm to tell the personal story. Later, in the group interviews, an official family version was presented. Perhaps, if the sequence was reversed, there would be more of a process in action if the personal story had to be told in a group setting with others commenting.

Conclusion

The findings of this study suggest links with other directions of research. For example, the hoping process identified would be compatible with the hoping self having a developmental history. This topic of research inquiry has only been explored recently. One could speculate that *walking the tightrope* fits in a larger developmental process. Jevne (personal communication, August 8, 1994) has wondered if there is a hoping process beginning in infancy with something like Erikson's *trust vs. mistrust* stage of development.

Researchers have only begun to explore the nature of hope. In this study, questions are raised about whether hoping changes or our access to our hoping changes throughout our lives. Is the lack of hope really a lack of access to hope? Are fear and suffering necessary to obtain access to one's hoping? If fear and suffering are necessary, are measures taken to alleviate these feelings counter productive? Is there a biological basis to hoping? Is hoping a sort of neurochemical response or antidote to fear and suffering? Are there religious practices or cultural patterns that promote the hoping process, or hinder it? Can a person have a value system that makes hoping more or less likely? Can hoping be an individual phenomenon or must it always occur in connection with others? What might the nature of that connection be? How do nurses participate in that connection? How does hoping affect the course of schizophrenia? The person with schizophrenia frequently suffers terrible fears- would hoping act as an antidote if fears are rooted in a pathological process? Can hoping be measured? Does hoping exist only at the level of symbols and in the unconscious mind? This is just a brief list of questions and each question triggers many more questions.

Tennant's (1993) survey of nursing literature over the past 40 years found that the role of the family was usually devalued by mental health nurses. A motivation for doing this study was to identify a healthy process that would provide insight into the ways nursing practice could focus on wellness. In the distant past, nurses often replaced the family and the psychiatric unit replaced the home in a community. Today, the person is usually either home with their own family, living alone with some supports, or in a group home. The nurse is not part of a substitute family in the hospital and a body of knowledge related to topics like milieu therapy is often no longer applicable. This study is appropriate to the future practice of mental health nursing. There is a need to understand how families can thrive in difficult circumstances and how nurses can be with them in a way that promotes that thriving.

I have used the metaphor of 'walking a tightrope' as the core variable in the process identified by this study. It evokes the danger of falling, the courage, and the skill of walking. These families are sometimes given much less respectful descriptions of their experience by the nurses they encounter. If they want effective treatment of the illness, they risk being labeled as demanding or unrealistic. If they are in turmoil due to grieving and coping with enormous difficulties, they risk being suspected of having inadequate family dynamics. If they do manage well, they are seen as being simply normal and ignored instead of extraordinary and worth learning from. One of the important implications of this study is to revise the images that are commonly assumed about these families.

The managers of mental health nursing are also moving from the highly structured hospital to community based teams. An understanding of the hoping process in families will help justify the work of nurses who do not perform measurable tasks. Not every person with schizophrenia has a supportive family and there is a need to assess and plan the type of care that needs to be provided. An understanding of the hoping process offers another way to evaluate the helping process in group homes and other forms of supported community living.

The education of nurses could include various techniques that allow students to become aware of their own hoping processes. This exercise in self awareness would increase the student's sensitivity to the hoping process in the family's of people with schizophrenia. If the students seriously consider what would be helpful at this point in their personal process, they will have a more appropriate approach to the families they encounter in practice.

The majority of research in the past 25 years has looked at these families to discover a causal relationship with schizophrenia. No such relationship has been found. It is much more likely that families have a potential to contribute to the well being of the person with schizophrenia than to the pathology. Future studies could build on what was found to identify specific approaches that are helpful at each point in the process. Rather than look for the type of interventions found in care plans, there is a need for in-depth understanding. The assumption made by writers of care plans is that there are generic families with generic problems. In reality, there are some families with incredible strengths developed in times of great hardship. They are the guides. When nurses connect with their hope, they will share the hopefulness instead of just seeing the possibilities of falling.

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Appendix A: Consent Form

UNIVERSITY OF ALBERTA
FACULTY OF NURSING
Information and Consent Form for Participants

PROJECT TITLE: Hoping in Families of People with Schizophrenia
INVESTGATOR: Daniel Scott RN, BA, BN

PURPOSE OF THE STUDY: The purpose of this study is to learn how some families of people with schizophrenia develop and maintain hope over time. Little is known about hope in families of people with schizophrenia. Hope is known to be a human response to loss and suffering. Hope helps people to endure difficult times in their lives. Learning about this process of hoping may help nurses improve the care to families of people with schizophrenia.

INVESTIGATORS:

Daniel Scott RN

Master of Nursing Student
Faculty of Nursing, CSB, 3rd. floor
University of Alberta
Edmonton, AB, T6G 2G3
TEL: (403) 432 0042

Dr. Olive Yonge (Thesis Supervisor)
Associate Professor
Faculty of Nursing, CSB, 4th. floor
University of Alberta
Edmonton, AB, T6G 2G3
TEL: (403) 492 2402

If you agree to be in the study, I will arrange to interview you at a time and place of your choosing. In these interviews, I will ask about your thoughts and feelings about hope. I will interview you from one to four times. I will do one interview with all your family together. Dr. Olive Yonge will be present at the family interview and making written observations. Each interview will be recorded with a tape recorder. Each interview will take between one to two hours. I would like to telephone you later if I need to clarify anything you said.

PARTICIPATION: There will be no harm to you if you take part in this study. There is a small chance that talking about the experience of hope in your family may cause some uncomfortable feelings. If this happens, the researcher or his supervisor will be able to give you information about counseling services. You will not benefit directly from this study. The results from this study may help nurses understand how families of people with schizophrenia find hope in their lives. This may help to improve the care that nurses offer to families.

You do not have to be in this study if you do not wish to be. If you decide to be in the study, you may drop out at any time by telling the researcher or his supervisor. Their telephone numbers are listed above. You do not have to answer any questions or discuss any subject in the interview if you do not want to. Taking part in this study or dropping out will not affect your relative's care.

Your name will not appear in this study. Only a code number will appear on any forms or notes. The researcher will delete your name and any other identifying material from the transcripts but this information may be left on the audio tapes. All records will be kept in a locked cabinet. The consent forms will be kept separate from the data and in a locked cabinet for five years. The tapes will be destroyed seven years after the study is completed. The typed interview and notes will remain in a locked file. They may be used for another study in the future, if the researcher receives approval from the appropriate ethical review committee. The interviews will only be read by the researcher and my supervisor. A typist will transcribe the taped interview into a written form.

The information and findings of this study may be published or presented at conferences. Your name or any material that may identify you will not be used. If you have questions or concerns about this study at any time, you can call the researcher at the number above.

CONSENT TO PARTICIPATE IN THE STUDY

I acknowledge that the above research procedures have been described. Any questions have been answered to my satisfaction. In addition, I know that I may contact Daniel Scott or Dr. Olive Yonge if I have any further questions either now or in the future. I have been informed of the alternatives to participating in this study. I understand the possible benefits of joining the study, as well as the possible risks and discomforts. I have been assured that records relating to this study will be kept confidential. I understand that I am free to withdraw from the study at any time. I further understand that if I do not participate in the study, or withdraw at any time, my relative's nursing care will not be affected. I understand that if any knowledge from the study becomes available that could influence my decision to continue in this study, I will be promptly informed. I have been given a copy of this form to keep.

(Signature of Participant)	(Date)
(Signature of Researcher)	(Date)

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name: ____________________

Address: ____________________

____

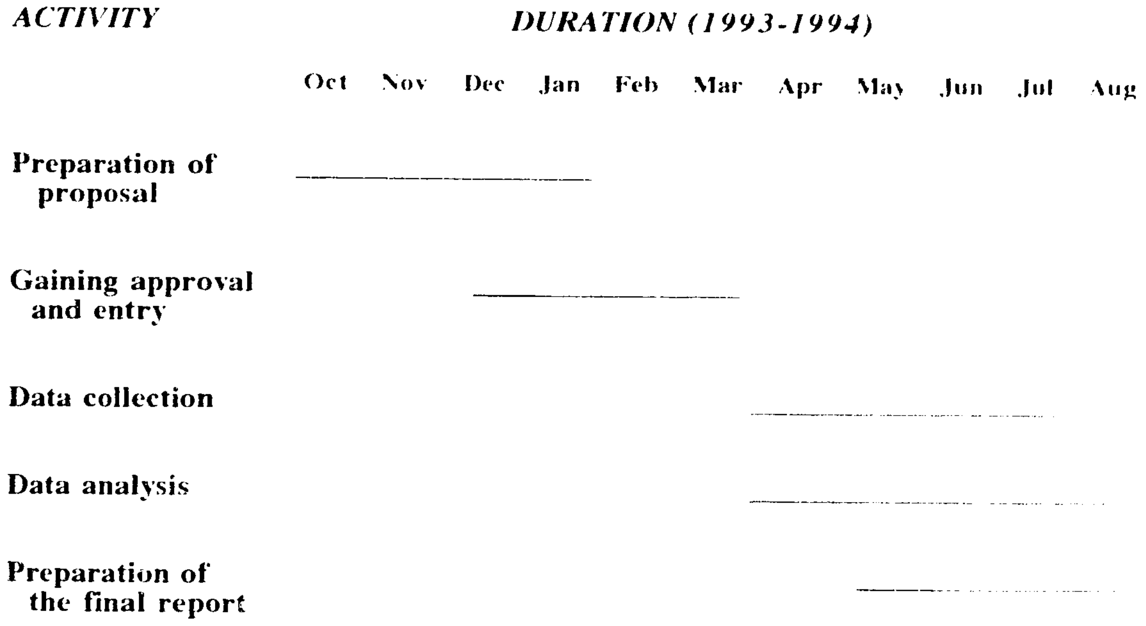
____

____

Appendix B: Data Collection Schedule

April 1	Group presentation notes	Nurses at University of Alberta Hospital
April 12	Taped interview	Researcher interviewed by Jude Spiers
April 15	Taped/transcribed interview	Individual interview: Betty
April 15	Taped/transcribed interview	Individual interview: Jim
June 1	Taped/transcribed interview Written observer's notes	Betty & Jim interviewed together, Dr.Yonge observing
June 15	Taped/transcribed interview	Individual interview: Jane
June 21	Taped/transcribed interview	Individual interview: Bill
June 28	Group presentation notes	Meeting of Schizophrenia Society of Albert
June 29	Unrecorded telephone call	Clarification: Betty
July 11	Taped/transcribed interview	Individual interview: Mary
July 11	Taped/transcribed interview Written observer's notes	Mary & Jane & Bill interviewed together, P. Belanger observing

Critical Path



Appendix C: Initial Interview Guide

The following are the prepared questions for initial interviews. The experience of other researchers studying hope is that people often tell their experience of hope in story form despite the types of questions asked. Areas of interest are the nature of hope, what promotes hoping, and how hoping has changed over time. In other words, questions are about where hope comes from, where it is directed to, and what evidence do people have for their hope.

1) "What do I need to know about your family to help me understand your hope?"

2) "When you began thinking about this illness, for the very first time, what did you hope for? How did those first hopes change?"

3) "Today, what do you think of those very first hopes?"

4) "Tell me a story about an experience that changed the way you hope"

5) "Some people find hope when everything seems hopeless, can you describe a specific occasion when this happened to you?"

6) "There are certain activities or habits that seem to be comforting during difficult times, does your family share any of these?"

7) "If you wrote a short story about how your family has hoped since the beginning, what would that story be like? Can you describe the main characters and the plot?"

8) "Hope often is a response to feeling trapped by a situation, can you tell me about a time when this was what seemed to happen?"

9) "How would you describe your hopes now?"

10) "Many people report that hope gives them energy to deal with troubles, if you feel more energetic, would you tell me about that? How would you describe your energy levels from the very beginning?"

11) "People often use images instead of words to describe hope. Does any particular image seem to describe your hope? At what point did this image start to describe your hope?"

12) "Some memories are often considered a source of hope. When you feel bad, do certain memories seem to help? Would you be give me an example?"

13) "Do you think each person in your family has their own unique hope or is there a shared hope among everyone or among some of the family? Would you tell me how this hope is shared? or Would you tell me why this hope is private and unique to each person?"

END

18-01-95

FIN