EXPLORING THE NEEDS OF FAMILY MEMBERS

DURING

A FIRST HOSPITAL ADMISSION FOR A MENTAL ILLNESS

BY

JOANNE WINSOR

A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

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Abstract

A first hospitalization for a mental illness presents a potential crisis for the family. The impact of hospitalization and illness is not isolated to the individual's experience and the effects on a family member during a crisis event can have many consequences. Very little current research has been done with a specific focus on the hospitalization in mental health and the needs of the family during that time. The purpose of this research study was to identify the needs of a family member or main caregiver during the first hospitalization for a mental illness. Crisis theory was chosen as a conceptual framework to maintain the focus on the limited time of hospitalization. Three areas, consistent with crisis theory, were used to develop the research study and included the family member's perception of the event, the support system during the event, and the coping mechanisms identified during the event. This information is important to nursing for a number of reasons and is integral to providing excellence in care. A qualitative methodology was chosen to guide the study and resulted in rich descriptions of the perceptions and experiences of family members' involvement in mental health programs. Ultimately, recommendations to enhance and expand clinical nursing practice in mental health programs were developed.

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Chapter One: Introduction

The perspective of clients and families is an important consideration in the evaluation of mental health programs. Therefore, exploring family members' experiences and appraisals of services is vital to ensuring the needs of families and clients are met. In 2000, The Canadian Council on Health Services Accreditation (CCHSA) identified several factors as indicators for the evaluation of mental health programs. CCHSA document included the following statement:

> The appraisals of mental health consumers/families are an important source of information regarding user' experiences with services, service providers and service coordination. Satisfaction is an indication for the extent to which services and supports meets the needs of clients and families, and is considered a key dimension of service quality (McEwan & Goldner, 2000, p. 37).

Over the last five years, the Winnipeg Regional Health Authority [WRHA] Mental Health Program has conducted annual in-patient satisfaction surveys and recently started to survey family members. To add to this accumulating body of information, further exploration of the family members' perspectives on in-patient services, especially family members who are interacting with mental health services for the first time, was identified as a priority.

This perspective is a fairly new in evaluating services. It is only in the last 10 years that an interest in the views of consumers in the health care setting has been expressed (Howard & El-Mallakh, 2001). While this interest grew in many different health care settings, interest in the views of consumers in the mental health care setting

has lagged (Ruggeri, 1994) or these views simply have been excluded with no explanation offered (Abramowitz, 1987; Nelson & Larson, 1993). Despite the recent change to include the consumer, the inclusion of family members' perspectives has been even slower in evolving.

Family members' perspectives must be taken into consideration in the provision of mental health care for a number of reasons. From a practice standpoint, it would be beneficial to know the needs of family members when an individual has been admitted for the first time. Examining the perceptions of family members who are new to the mental health system may prevent problems by fostering more positive relationships between mental health care providers and the family members. It is likely that a positive experience during the first encounter will help in meeting the needs of the family members and clients during subsequent visits. A negative experience may ultimately be harmful to the future experiences with the mental health care system and impede the development of a therapeutic alliance.

Understanding whether or not a service is meeting the needs of the family is an intricate process. It cannot be assumed that the needs of the family and family members are met just because the family member states he or she is pleased with a service. It is imperative that health care professionals have an understanding of the needs of family members.

Winefield, Barlow, & Harvey (1998) completed extensive research demonstrating changing caregiver needs over time. They noted that the needs of the caregivers, who were often family members, were different closer to the time of diagnosis than they were

later on. Levine & Leginza (2002) also looked at the needs of family caregivers during times of crisis. The crises were typically associated with a hospitalization or exacerbation of symptoms. Levine and Leginza initially wanted to conduct focus groups with families at the time of their first admission to hospital. The ultimate aim of the study was to develop recommendations to meet the needs of families. However, this proposal was met by opposition from other health care professionals, who felt it was an inappropriate time to recruit families due to the level of stress the families were under during a first admission. Of particular interest in the discussion of the findings, the researchers reported that, although the structured focus groups were supposed to discuss a variety of transitions and crises over the course of the experiences of hospitalizations, the families spent more time talking about the first time they realized something was wrong (usually the first hospitalization). The families "seemed to remember it most vividly and were most profoundly affected by it" (Levine & Leginza, 2002, p. 348). Clearly, the first hospitalization is a particularly important or significant time for the family. However, studies which report families' reactions to a first hospitalization are rare. Researchers specifically exclude newly-diagnosed clients and their families, which suggests that the experiences of newly-diagnosed patients and first treatment episodes represent a unique and under-described event (Rose, 1983, 1998).

The needs of families also have changed with the changes in the health care system and practice. Increasingly, families are providing care after hospitalization and, therefore, should be part of the hospitalization and treatment plan to ensure the continuity of care. Furthermore, with the availability of early interventions in the treatment of

psychosis, families are presenting earlier for treatment. "Younger patients are more likely to be living with and dependent on their parents, and the parents are likely to be motivated and enthusiastic about their involvement with the treatment of an adolescent or a young adult in comparison with those families who have been exhausted by the fallout from chronic psychotic illness" (Malla & Norman, 1999, p. 396).

The only Canadian research with the expressed purpose of evaluating an in-patient mental health service to address the needs of family members was conducted by Wallace, Robertson, Millar and Frisch (1999). The recommendations arising from the focus groups of family members resulted in multiple changes to address the needs of the families and clients. The changes were practical and included the management, function and environment at the in-patient facility. For example, Wallace et al. (1999) found a concern of the families surveyed to be a lack of recreation on the unit, and subsequently the nurses started daily walks. The recommendations appeared to be related to patient care and not to the needs of the families.

For an evaluation to be useful to a particular program it needs to be site-specific. Mental health services are not all homogenous, given the multitude of factors including funding, the proximity of resources, and the health care system in general that may vary between sites. It is useful to know how families evaluate services available in the United Kingdom or in parts of the United States. However, conclusions cannot be drawn about services or families' needs in Winnipeg based on such different health care systems and populations. If changes have been identified in the United Kingdom as being needed to improve the mental health system to meet the needs of families, it would be irresponsible

to transfer the recommendations to an alternative site unless it could be determined that the same needs exist or if similar changes would be beneficial. Certainly, previous research may give us templates or suggestions for exploration. Nonetheless, if we want to evaluate and improve the current mental health system in Winnipeg, it is reasonable to focus research on family members who have had experiences with the mental health system in Winnipeg.

In keeping with the Winnipeg Regional Health Authority's recently implemented initiative on increasing consumer and family involvement in policy planning (WRHA, Adult Mental Health Program, 2004), the WRHA attempted to have family members evaluate current hospital-based services in mental health programs. Unfortunately, there was a poor response rate and few conclusions could be made about the degree to which hospital based inpatient mental health programs met the needs of family members (D. Clarke, personal communication, July 14, 2004).

Purpose of the Study

The purpose of this research study was to identify the needs of a family member or a main non-family caregiver during the first hospitalization of a patient requiring in-patient care. It is important to clarify that this research is considered 'family-related' and not 'family research'. "Family-related research derives data from individuals and explores relationships among family members whereas family research focuses on the family unit as the entity of investigation" (Doornbos, 2002, p. 40). It was not the intent of the researcher to interview the entire family unit, but to invite the one member who was most involved with the hospitalization to be interviewed. The interviews focused on

three areas related to the family member's experience, and included the family member's perception of the event, the support system during the event, and the family member's coping mechanisms identified during the event. The intent of this research was to uncover the needs of the family during a crisis period through the exploration of the experience of a family member. Ultimately, development of recommendations for mental health care professionals and how they may address the needs of the family followed from the analysis of the data.

Crisis Theory

It is often recognized by health care professionals, and certainly by family members, that initial diagnosis of any illness including mental illness often represents a crisis for the family. Families with no experience with mental illness are unsure of what to expect and have extensive learning needs, whereas families who have a history of mental illness are plagued with the questions as to the course of the illness and to what extent their family member will be affected. This represents a tumultuous time and can lead to a crisis situation.

Conceptual framework.

The main theoretical approach used for the study was Crisis Theory. Several theories and frameworks were reviewed before choosing crisis theory, including Barnhill's framework for healthy family systems (Kuisma et al., 1997), Family Resilience (Walsh, 1996), Family Systems theory (Friedman, 1992), and Family Stress and Coping Framework (Rungreangkulkij & Gilliss, 2000). These frameworks all focused on the family in a holistic manner or had a specific focus within the family system such as

dynamics (Kuisma et al., 1997). Despite the various frameworks, Crisis Theory was most appropriate considering the focus of this research is to explore the needs of the family member during a first hospital admission in mental health which has the potential to become a crisis event. To ensure the practicality of the data being sought and the anticipated recommendations to be derived, Crisis Theory was considered the best option to maintain the focus on the limited time of hospitalization.

Crisis theory maintains that a crisis event can be viewed as either an opportunity or a threat. Aguilera and Messick (1986) further explain that the main danger of a crisis event is that the family and/or individual in question may have their mental health affected in a negative manner. On the other hand, the crisis event may present the opportunity for families to learn and they may be more amenable to other available therapeutic interventions. Either way, a state of disequilibrium can occur following the event where the individual and family must adapt to the event and subsequent problems, or adjust to a non-solution. Ultimately a state of new equilibrium must be established.

The theoretical framework (see Figure 1) is generic enough to be used in a variety of different situations. It starts with stresses threatening the equilibrium of the individual and family. When the stresses cause a state of disequilibrium, there is a need to restore equilibrium. Balancing factors are identified as those areas that have an influence on the ability of an individual to re-establish equilibrium. The balancing factors include the perception of the event, situational supports, and coping mechanisms. They may be distorted or inadequate, ultimately influencing the ability of the family or family member to establish a new equilibrium. If a new equilibrium is not established, the result is a

crisis.

The perception of a situation is based on multiple appraisals of the situation and to what degree stresses may pose a threat to the equilibrium of the individual. A given situation may be viewed as a threat to life or a life goal. The perception of an event or situation is closely connected to coping behaviors. According to the framework, an individual will choose different methods of coping, based on how a situation is appraised and re-appraised. Coping behaviors are highly individual and may include a variety of methods used to alleviate anxiety. Available coping mechanisms are what people usually use when they have a problem. They may respond emotionally by crying or expressing anger or they may attempt to problem-solve their way out of the dilemma. Further, some may react by temporarily withdrawing from the situation to reassess the problem (Aguilera, 1998, p. 39).

Situational supports are defined by Aguilera (1998) as "those persons who are available in the environment and who can be depended on to help solve the problem" (p. 37). Situational supports persons who are accessed can also provide appraisals of the situation which may or may not reflect the appraisals of the individual. Through interactions with the situational support person, the individual may be affirmed that he/she has made the correct appraisal or, if there is a lack of congruence with the situational support person, reappraisal may occur. These interactions may then start to influence the coping methods used. The process is cyclical with perceptions, coping behaviors and situational supports changing many times as reappraisal of a situation occurs and perceptions are altered based on new information.
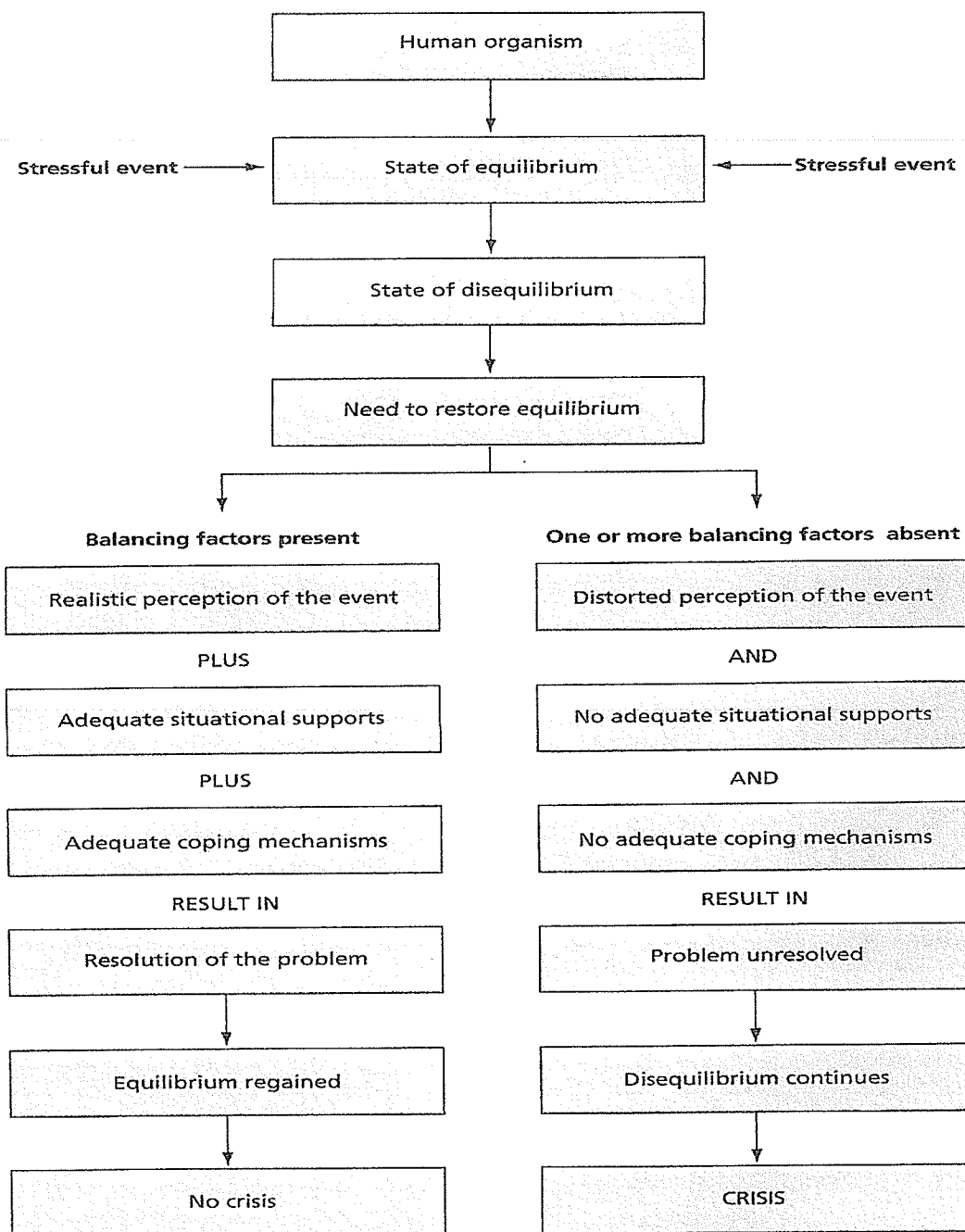
Figure 1. Depiction of Aguilera's paradigm for representing the relationship of balancing factors in a stressful event. Reprinted from Crisis Intervention: Theory and Methodology (8th edition), Aguilera, D., Page 33 Copyright 1998 by Mosby Inc., with permission from Elsevier.

Researchers have noted the usefulness of this framework in working with families. For instance, Woolley (1990) was able to successfully implement crisis theory to assist nurses to effectively intervene with families in critical care. Similarly, Moore (1989) employed crisis theory with families of hospitalized children and found the process to be similar to the nursing process as well as practical in guiding interventions; she used Aguilera and Messick's (1986) balancing factors as a framework for initial assessment and data collection. In the current study, these balancing factors included the family's perception of the event, the family's support system, and the family's available coping mechanisms. These balancing factors were used to develop the questions for the semi-structured interviews (Appendix A) and to frame the research questions. On completion of the research, it is anticipated that practical interventions can be developed to ensure that the hospitalization experience is more of an opportunity and less of a threat to the patients and their family.

The Research Questions

The research questions identified in this study included:

1. What was the perception of the event by family members during the crisis period of the first hospitalization?

2. What were the available support systems for family members during the crisis period of the first hospitalization?

3. What were the coping mechanisms used by family members during the crisis period of the first hospitalization?

4. What were the family members' needs during the crisis period of the first hospitalization?

5. What can health care providers do to address the needs of family members during the crisis period of the first hospitalization?

Significance of the Study

These data are important for a number of reasons. A first hospitalization presents a potential crisis for the family. The impact of hospitalization and illness is not isolated to the individual patient's experience and the effects on the family member during a crisis event can have many consequences. These consequences may be health-related or create issues involving quality of life, not just for the family member with the illness, but varying implications for the entire family. Little current research has been done with a specific focus on the hospitalization in mental health and the needs of the family during that time (Levin & Ligenza, 2002; Moore, 1989).

Some of the effects of the patient's illness on their family members are identified in the literature. The effects may include influencing the delicate relationship between the family member(s), health care providers (carers) and the patient. Indeed, the quality of the relationship between carers and the patients seems to depend on relatives' appraisal of their circumstances (Scazufca & Kuipers study as cited by Veltman, Cameron & Stewart, 2002). This would mean that the relationship between health care providers and an ill family member can be directly affected, by the perceptions of the family member. Therefore, a positive relationship needs to be established between the family and health care providers to ultimately enhance the relationship between the patient and the health

care providers. Current research also suggests that mental health care that includes interventions aimed at the family also results in reduced relapse rates (Sellwood, Barrowclough & Tarrier, 2001). Reduced relapse rates can have a profound impact on the functioning and quality of life of family members and of the individual with a mental illness. Reduced relapse rates mean less disruption to the family in terms of their daily schedules and to the overall impact of the illness on the family. A relapse increases costs to the health care system and to society if more appointments are needed to see a physician for medication alterations or, even more costly, a hospital admission for stabilization.

Unfortunately, the literature has shown that the needs of the families are not being met by community or in-patient mental health services, to varying degrees (Aubry et al., 2000; Kasper, Steinwachs, & Skinner, 1992; Wallace et al., 1999; Hill, Shepherd & Hardy, 1998). When the needs of the family members are unmet, families report being dissatisfied, they report poor communication with health care professionals, and positive relationships are hindered. These outcomes are not congruent with what is needed to ensure adequate care, support, and adherence to the treatment program for the benefit of the ill family member and the family as a functioning whole.

Chapter Two: Literature Review

Few individuals would argue about the importance of the family. When one

family member is ill, the family takes on a new dynamic and often becomes the main

support for the individual. Over the years, the definition of family has changed and holds

many different connotations. From a nursing perspective, the 'family' is who ever the

client identifies as family and yet legally the family typically includes blood relations

only or those through legal marriage. In the health care setting, families are verbally

touted as being important and yet they are often labeled as difficult or over-involved and

their support minimized by the health care system.

Deinstitutionalization is long since over and now a new generation of families

with family members (newly) diagnosed with a mental illness is struggling in a health

care system operating under former influences and history. Where does the family

belong? We know they are important, we know they are often the main caregivers, but

where do they fit into our practice and more importantly, as health care providers, what is

our responsibility to the family of our patients? Health care professionals are struggling

with these questions and, with time and research, the changes that are long overdue will

hopefully be implemented. One area in need of exploring is the needs of families during

an initial hospitalization in mental health. These needs are recognized as unique,

especially in a crisis situation. Through this exploration, practical recommendations will

facilitate some of the changes necessary to transition our practice with families.

Although not initially intentional, crisis theory and the framework as proposed by

Aguilera (1998) guided the organization of the literature review much as it informed the

research as a whole. The three balancing factors of Aguilera's (1998) crisis model were

used to assist in outlining the literature review. The literature (and the crisis model) is largely divided into three categories: perceptions of the family/family member; supports of the family/family member; and coping of the family/family member.

The Families' Perspective

Despite a policy statement having been made by the Canadian Council on Health Services Accreditation (CCHSA) to include families in the evaluation of services, it does not necessarily mean the sentiment has been translated into practice. Evans and McGaha (1998) examined the level of involvement and knowledge of families regarding mental heath care policy and reform in Missouri. Families were surveyed by accessing an advocacy group newsletter, which meant 83% of the sample also reported belonging to an advocacy group. Despite this high involvement in mental health advocacy, they found families had difficulty understanding information given to them about a new policy in Mental Health. They concluded from the survey that, although policy makers and health care professionals state it is important for families and clients to be involved in policy and program evaluation, families and clients are rarely true partners in the health care system and ultimately lack the degree of power necessary to effect major change. It is unknown to what degree families feel a part of the mental health care system in Winnipeg. It remains unclear if there are sufficient resources to meet the needs of the families using them. It is unknown if families are true partners in the health care system and have they the power to effect change through involvement in program planning and evaluation.

Research on the Families' Perspective

Research exploring the perspective or experiences of the family and family

members in mental health continues to add to the body of knowledge. Areas that have

been studied relate to quality of life (Corring, 2002), involuntary commitment (Hatfield,

1993), the caregiver role (Milliken & Northcott, 2003; Rose, 1998; Stern, Doolan,

Staples, Szmukler & Eisler, 1999), interactions with mental health services (Doornbos,

2002; Lukens, Thorning & Lohrer, 2002), and issues related to the transfer of psychiatric

inpatients (Shugar, Smith, & Katz, 1992). This is in no way an exhaustive list. However,

it is noted that most of the research centres on concepts relating to the caregiver role.

More recently, researchers are taking an even broader approach, exploring the lived

experiences of families and family members who have a family member with a mental

health diagnosis (Nystrom & Svensson, 2004; Saunders, 2003; Teschinsky, 2000).

Hospital setting versus the community.

When looking at program evaluation and addressing the needs of family

members, the studies specifically of interest are those which focus on the experience in

the hospital setting. There is a dearth of available research examining the hospital setting

experience for families. However that which is available provides a mixed view of how

families perceive or rate current in-patient mental health services. Solomon and

Marcenko (1992) reported on the satisfaction of the families of adults discharged from a

psychiatric facility when the facility was being permanently closed, and found "families

indicated high levels of dissatisfaction with the hospital in terms of teaching them about

medication, teaching them to help motivate their relative, providing practical advice on

how to cope with their situation, providing assistance in crisis, and giving them emotional

support" (para, 32). Hatfield, Gearon & Coursey (1996) compared the values families

placed on hospital-based programs and community based programs, showing the latter as

rated higher. In direct contradiction, Hostick (1998) reported that family members were more likely to make positive statements about hospital programs and negative statements about community programs within a focus group setting. There would appear to be little agreement amongst researchers, and with varying mental health programs available in different countries, added to the small sample sizes and different methodologies, few conclusion can be drawn. Ultimately the number of studies with a family focus is scant in comparison with studies eliciting clients' perspectives and the concentration remains on community based programs (Ruggeri, 1994).

Hospital setting and family perceptions.

Some researchers, in their endeavor to explore experiences of families, were able to add valuable information to the perception of the in-patient setting, whether or not it was the expressed intent of the study. Ferriter & Huband (2003) examined the experiences of family members who had a son or daughter with a diagnosis of schizophrenia and currently admitted to an in-patient mental health program. The reason they accessed their participants in this manner had more to do with convenience than ensuring the family was involved with an in-patient unit. Ferriter and Huband purposefully excluded newly diagnosed families, and stated the focus during the interviews was to look at experiences over time because looking at a specific incident "might overemphasize the burden of recent crises" (p. 553). The family members ultimately reported a perceived lack of information and related that they felt guilty even in the absence of blame from health care professionals.

The initial contact with the health care system and professionals is so much more important when the family and client have not had any experience with these areas

before. Often the patient has not yet received a diagnosis and therefore there may be confusion, speculation, and perhaps concern for the worst possible scenario. The hospital admission process was a focus for exploration by Scharer (2000) and also illuminated many insights into the hospital setting. Scharer looked at the perspectives of parents and nurses through interviews; she strongly argued that this initial contact point would set the stage for the relationship between the family members and health care providers. Scharer (2000) also identified that "parents' expectations and prior experiences with psychiatric treatment were important influences on the nurse-parent relationship" (p. 735). Initial contact therefore provides an opportunity to explore the expectations of the family, clarify roles, and ultimately contribute to a more positive relationship. Scharer's sample included first time parents as well as those who had been through the admission process many times. There were several noted differences in the expectations of the 'first timers'. The first time parents often based their expectations on preconceived stereotypes or media examples of the health care professions and the hospital mental health setting. The individuals in her sample who expressed the strongest negative perception/experience with the admission process were notably individuals who had not had previous experience in health care and had expectations that were not met. These expectations involved the admission process and how the family members thought the hospitalization should progress. For example, one father thought the admission process was excessively lengthy while another mother was surprised to discover she could not remain with her son overnight. This only highlights the importance of the first time admission to a mental health care setting, showing the needs of the family are unique at this point of contact and in need of clear communication with respect to expectations.

Perspectives of Health Care Providers

Kaas, Lee & Peitzman (2003) stated clearly that "there is a paucity of information regarding what modern mental health care professionals think and believe about the families of persons with mental illness and how they act toward them" (p. 745). Kaas, Lee & Peitzman (2003) surveyed health care professionals to identify perceived barriers to collaboration with families. Their results, although intriguing, might be considered disappointing. The barriers identified included: "lack of time,… their own feelings of conflict about treating the client versus treating the family,…[and] beliefs that family involvement may be harmful to the client and that there is a lack of visible or measurable results of the benefits of including families in the fare and treatment of the client" (p. 747).

Sharer's (2000) research as previously discussed, reported how nurses view the admission, even the first admission of a newly or undiagnosed patient, as being 'routine'. This raises concerns and questions about the level of understanding health care professionals have of the families' perception of the experience. Lincoln, Harrigan & McGorry (1998) expressed a need for mental health care professionals to learn from families who are newly exposed to the mental health care system to provide better services on a variety of levels. Nystrom & Svensson (2004) in their study of fathers' experiences with the mental health care system noted the health care professionals "at the first psychiatric consultation appeared to be totally unaware of the trauma the fathers experienced prior to and during their children's first hospitalisation" (p. 369). Health care professionals have yet to grasp a full understanding of the families' first time experience with an in-patient mental health care program and may be significantly

contributing to the needs of the family not being met and the therapeutic relationship not being formed.

The literature is littered with extensive criticism that the family has not been included in the care or treatment of their ill family member (Veltman, Cameron, & Stewart, 2002). Jubb & Shanley (2002) outlined several reasons why caregivers are not fully involved in the care of a family member during hospitalization. The reasons included the use of the traditional medical model which places the focus and emphasis on the patient and not the family, doubt about the benefit of the family by health care providers, and families' previous negative experiences with health care providers. Gasque-Carter & Curlee (1999), in examining the needs of family during hospitalization in a long term care facility, cited barriers to involving family may be the billing system as it may not be possible to bill for providing support or education to family members. Veltman, Cameron & Steward (2002) in their research offered the families' perspectives of being excluded. "The wife of a patient with bipolar disorder summarized the sentiment of most of the caregivers interviewed when she said, 'The legal and medical system cares for patients only, not for the caregivers. As a caregiver you're always fighting the system'" (p.111). They found negative and positive aspects of caregiving but predominantly negative information was reported about the mental health services available which were commonly referred to as 'the system'.

Historical Perspective of Family Involvement

Some of the reasons for exclusion of the family from the health care system may be historical. The history of families in mental health is remarkable, and much of this history shows families isolated from their family members who were admitted to 'mental

hospitals' which were largely used to warehouse the mentally ill. The idea of having a mentally ill relative remain in the home was unheard of, and often the care for that individual was thought to be best left in the hands of the professionals. This was further reinforced during the wide acceptance of prevention theories in the late 1960's and 1970's where blame for mental illness was largely assigned to families and communities (Camann, 1996). Prevention theories surmised that illness, including mental illness, could be prevented if early interventions were implemented. This assumption turned the focus to the environment, thus blaming the family or social situations for an individual's mental illness. Again, to remove someone from an unhealthy environment, which was thought to have caused the individual's illness, made the most sense following these theories.

Research during this time reinforced these thoughts amongst health care providers especially in the area of expressed emotion (EE). Behaviors exhibited by some family members, most often the mother, included "criticism, hostility and overinvolvement – were termed expressed emotion" (Marsh, 2000, p.3). Beginning in the 1970's there were observations that some clients who had families with high emotionally over-involved characteristics had higher relapse rates. Continued research completed in this area over the last thirty years led professionals and researchers to see the family as potentially exacerbating the client's illness. Therefore, families were viewed as having a negative impact on the client. More recently the research on EE has focused on first-episode psychotic patients and their families, suggesting the lack of predictability of EE (Linszen & Birchwood, 2000). The understanding of EE has shifted drastically and now EE is considered a coping strategy indicative of a family in a crisis situation, specifically in

families of first-episode psychosis, and not as the cause of the clients' illness or exacerbation of a mental illness (Sellwood, Barrowclough & Tarrier, 2001).

During the time of deinstitutionalization and "after years of forced isolation and a decade of blame, families were asked to do what expensive institutions and health care professionals have failed to do - provide care for persons with serious mental illnesses" (Camann, 1996, p. 482). Due to financial constraints, and when it became apparent that individuals with a mental illness did not miraculously recover once removed from the supposed cause of their illness, the mentally ill were released to the community with very few supports. The mass exodus from the large scale institutions meant that many of these individuals proceeded to live in the streets or in shelters. Those who returned to the family homes were met by family who were not equipped to handle the needs of someone with a mental illness. Today it is estimated that "one quarter to one third of persons with disabling mental illness live with family members and as many as 65% of all individuals discharged from inpatient psychiatric facilities return to live with a relative for varying lengths of time" (Skinner, Steinwachs, Kasper, 1992, p. 23). With so many patients residing with their families, it seems unfathomable for the family to be excluded from involvement in the care and treatment of their ill family member.

The nursing literature has reflected the history of the exclusion of family involvement in mental health. Tennant (1993) completed a review of nursing literature, as it related to families; she found that family is an important focus in the nursing literature in almost all specialty areas. However, there was an absence of reference to the family in the mental health nursing literature, more specifically, text books. The few authors, who discussed the family in their textbooks, portrayed them either as obstacles

or as adjuncts to care in a small way. The authors may have been influenced by the common beliefs or practices of the time, ultimately believing the family to be of blame or the family to be a nuisance to the care of the client. More recently Kaas, Lee & Peitzman (2003) also agreed, stating the use of dated texts and biases in literature or from educators perpetuate the barriers to accepting and working with the family.

There is, without doubt, a lengthy and negative history between the family and mental health care system, for a variety of reasons. It is time to adopt a new approach and to move on in practice to include the family. Research is now showing the benefits of involving the family in care, even to the point of decreasing relapse rates for the client (Falloon et al., 1998; Sellwood, Barrowcough & Tarrier, 2001). Involving the family in care usually takes the form of a program change to increase the participation of families (Dixon et al., 1998) or implementation of family education programs (Kazarian & Vandereyden, 1992).

Coping

Coping mechanisms are one of the balancing factors suggested by Aguilera (1998) as affecting individuals when they are faced with a situation causing disequilibrium. The coping mechanisms people use are highly dependent on the situation. For example, coping with the death of an individual may not 'look' the same as when coping with a natural disaster. Aguilera (1998) considered this when she defined coping "as a constellation of responses that serve to control or reduce emotional stress in the face of some externally imposed life strain, such as chronic illness" (p. 154). Aguilera cited and used the definition and conceptual understanding of coping as

introduced by Lazarus (1966).

Coping involves the cognitive process of appraisal whereby individuals continually appraise their situation to determine which coping behaviors are to be implemented. Perceptions are developed out of appraisals of a situation. In essence they are trying to determine what the situation means for themselves and sometimes their family (Lazarus and Folkman, 1984). Lazarus and Folkman (1984) identified appraisals as primary, secondary, and reappraisal. Primary appraisal is the determination that a specific event is either "irrelevant, benign-positive, or stressful" (Lazarus and Folkman, 1984, p. 53). Secondary appraisal occurs when the individual tries to determine what can be done to address the specific situation (Lazarus & Folkman, 1984) and may include employing coping mechanisms. Finally, reappraisal occurs when new information is obtained and offers the potential to change earlier appraisals. It is interesting to note that many researchers looking at coping also used Lazarus and Folkman's stress and coping paradigm as a conceptual framework (Neundorfer, 1991; Stolley, Buckwalter & Koenig, 1999). In a review of nursing abstracts, the most commonly cited framework was Lazarus and Folkman's.

Other researchers have attempted to provide definitions of coping. For example, Szmukler et al. (1996) reduced the concept of coping to coping strategies which are defined as "the cognitive and behavioral efforts aimed at controlling the demands imposed by the stressor" (p. 138). There are many different ways of categorizing and understanding coping in the research, albeit with similarities. Coping with an acute situation, such as a hospitalization, will elicit coping mechanisms which may be different than in other stressful situations. There is no currently available research specifically

looking at the way in which one family member copes during the first psychiatric hospitalization of another family member.

Understanding the coping mechanisms and styles of coping family members may use in a crisis will assist health care professionals when working with the family. For example, when it is noted that a family member is coping by actively seeking information, health care professionals need to provide information readily or, if they don't, they may exacerbate the situation by causing increased anxiety in an already anxious person. Health care professionals are also in a position to assist with assessing currently used coping skills or teaching new coping skills. In fact, Saunders (1999) recommended that "since families in crisis are disorganized and frequently unable to restore stability to the family system, nurses must learn to objectively assess a multitude of family processes, such as coping, psychological distress, patient behavioral problems, and family social support" (p. 108). Hill, Shepherd & Hardy (1998) were also able to identify the need for coping strategies when they concluded in their findings that caregivers caring for people with bipolar affective disorder wanted to know more about personal coping strategies. Huang & Slevin (1999) completed an extensive literature review of varying aspects of caregiving, including coping. The result was several recommendations for health care providers to provide interventions when working with caregivers who live with someone with schizophrenia. From the few surveys Huang and Slevin (1999) could find specific to mental health, they compiled coping strategies into three categories: psychological, physical, and social.

Caregivers and their coping behaviors or styles have been studied mostly in areas other than mental health. These areas include Alzheimers (Morano, 2003), cancer

(Nikoletti et al. 2003), dementia (DiBartolo & Soeken, 2003), brain injury (Man, 2002), HIV/AIDS (Baker, Sudit & Litwak, 1998), Parkinsons (Sanders-Dewey, Mullins & Chaney, 2001) and palliative care (Brinson & Brunk, 2000). However, the literature pertaining to how family members cope with mental illness is undefined. Ways in which researchers have operationalised coping includes caregivers' perception of their situation (Abe, Kashiwagi & Tsuneto, 2003), seeking information (Nikollett et al., 2003), emotion-focused coping (Butt, Strauss, Smyth & Rose-Rego, 2003), and problem-focused coping (Morano, 2003; Samuelsson et al., 2001). Recently, there has been great interest expressed in the relationship with coping style and the effect on the mental health of caregivers (Morano, 2003; Theileman, 2001).

Examining studies of coping does not necessarily elucidate how family members cope with an acute event such as hospitalization. The ability of a family member to fully appraise a new diagnosis such as schizophrenia – especially with little or no prior exposure to it – would be minimal at best. Literature on caregiving, although scant in mental health, generally looks at caregiving and coping behaviors over time but well removed from an initial hospitalization acute period (Huong & Slevin, 1999; Karp & Tanarugsachock, 2000; Szmukler et al. 1996; Yamashita, 1998).

Support

The term 'support' can be as broad as 'coping'. Aguilera (1998) defined situational supports as "those persons who are available in the environment and who can be depended on to help solve the problem" (p. 37) and it is the last balancing factor to be discussed. Support is not just a person but a person who is 'available' to the individual in need. Furthermore, that person must be depended on – meaning a trusting relationship

exists where they help solve the problem. Helping to solve a problem could involve providing information, listening, or other similar behaviors. "Most researchers concur that social support refers to social interactions that are perceived by the recipient to facilitate coping and assist in responding to stress" (Letvak, 2002, p.251). Providing situational support is not as simple as joining a support group or talking to a nurse; it is a complex activity and is equally complex to research.

It is logical to assume that support is beneficial, especially when it is identified as something that family members need and want. Letvak (2002), in her review of caregiving literature, stated "in recent years, recognition of the importance of social support to decrease stress and enhance coping has become widely recognized by both health care professionals and the general population" (p. 250). Similarly, Chambers, Ryan & Connor (2001) suggested, through their examination of caregiving literature, support provided to caregivers, especially in stressful situations, can have a positive impact on the well being of the caregiver. A Canadian empirical study initially hypothesized that caregivers who perceived they were receiving support would also show lower levels of psychological distress. However, caregivers who reported having more support from friends and family were associated with a "higher level of psychological distress" (Provencher et al., 2003) than those who did not report a perception of support. The researchers were surprised by this finding and suggested that caregivers may have sought support from friends in times of crisis when they were struggling with severe psychological distress. Support from friends then became an indicator of the stressfulness of the caregiving situation rather than a coping resource (Provencher et al., 2003, p. 602). Research is not yet available to clarify the previously stated study and

how perceptions of support affect psychological distress. What Provencher et al.'s study does illuminate is the recognition of a crisis event as a unique event which may have an impact on perceptions of support. In general, however, providing situational support is considered positive and beneficial to the family.

Caregivers have a greater need for support than other members of the general population. Various aspects of caregiving can affect every aspect of life from perceived burden to quality of life. Hill, Shepherd and Hardy (1998) examined the impact of caring for someone with a mental illness. A negative impact on caregivers' relationships with friends and social lives were reported by nearly "half (47%, n=470) of respondents and only a very small proportion (17%, n=170) reported a positive change" (p. 615). Jubb & Shanley (2002) completed a needs assessment of family caregivers and concluded a lack of information provided to families continued to be a neglected area as well as the "provision of emotional support" (p. 50).

Families continue to identify their need for continued support from health care professionals, which means that health care providers may not be meeting this need or perception of need. Cradock, Young & Forquer (2002) had family members identify and rate outcomes of a mental health program. The top three outcomes families wanted included "supportive and understanding clinician"..."effective medication with few side effects"... [and] "an excellent relationship with family" (p. 259). However, Ferriter & Huband (2003) examined the degree to which families rated health care professionals when providing support to the family. They found that support groups and family were identified as being the most helpful, while health care professionals were perceived as being the least helpful.

Families also identified wanting increased collaboration with health care providers. Doornbos (2002) took a qualitative approach by asking open ended questions of families to identify supportive and non-supportive aspects of the mental health care system. She did not specify a definition of either term but obtained strikingly similar themes from the survey. Doornbos (2002) concluded non-supportive aspects of the mental health care system as being "around communication difficulties whereby caregivers were unable to obtain pertinent information or were excluded from the planning of care" (p. 42). Families, in looking for support from health care providers, perceived health care providers as being unavailable as evidenced by a lack of communication. When she asked what was supportive about the mental health care system, she stated that "it is interesting to note that there was also a strong negative response to this question whereby 34% of caregivers found nothing at all supportive about the system" (p. 43). As well, 82% of Doornbos' surveyed respondents requested support and education for themselves as caregivers. Doornbos' qualitative approach was unique, as Wackerbarth and Johnson (2002) noted caregiving research has been dominated by quantitative methods, ultimately ignoring the experiences and personal accounts of various aspects of care giving, including support needs.

The current literature suggests health care providers are not identified as supportive. To further add to this issue is the suggestion that knowing how caregivers perceive and appraise support may be more important than the support itself. "The individual's subjective belief that support is available is the better predictor of major outcomes than are objective measures of the identified supports" (Letvak, 2002, p. 252). Clearly, the need exists to provide support to family members, as caregivers continue to

identify this as an area lacking in the health care system. The benefits of providing support are widely recognized for caregivers and families. What is not understood is the specific support needed by families during a time of initial hospitalization.

Summary

From a practice stand-point it would be beneficial to know what the needs are of a family member who has a family member admitted for the first time. These needs encompass coping and supports. Examining the perceptions and feedback of family members who are new to the mental health system will provide information to health care providers and ultimately act as a preventative step to ensure a positive relationship is fostered. Health care providers need to understand the experience from the perspective of the family members. This can be accomplished by engaging the family in a discussion of their perceptions and needs. Support and coping are intertwined with perceptions and interact in a cyclical manner. Understanding what families need and current use of support and coping mechanisms will strengthen the ability of health care providers to understand the experience and provide appropriate interventions when needed.

Chapter Three: Methodology

This chapter presents the research design, the methods for participant selection, data collect, and data analysis. Rationale for the decisions made in the research design is included. A discussion of methods used to ensure the qualitative paradigm was maintained by the researcher and methods to ensure rigor are also included. Finally, the ethical considerations and a brief introduction of the limitations of the design are presented.

The Research Design

This descriptive, exploratory study of family members' needs was designed within the qualitative paradigm. Creswell (1998) outlined several reasons for selecting a qualitative approach. Two of these reasons included the nature of the research question and the need for the topic to be explored. All five research questions in the current study (see Chapter One) started by asking 'what' were specific circumstances surrounding the initial hospitalization. The overall intent was to gain a deeper understanding of the experiences of family members.   A deeper understanding is required because, as shown in the literature review, little is known about the family members' needs during a first hospital admission in a mental health care setting. Morse and Field (1995) explained "qualitative methods should be used when little is known about a phenomenon, when the investigator suspects that the present knowledge or theories may be biased, or when the research question pertains to understanding or describing a particular phenomenon or event about which little is known" (p. 10). Therefore, the qualitative paradigm was most

suited to explore the experiences of family members and provided the attributes necessary for the methodology.

Streubert and Carpenter (1999) clearly described the common characteristics of qualitative methodology research which included:

> (1) a belief in multiple realities, (2) a commitment to identifying an approach to understanding that supports the phenomenon studied, (3) a commitment to the participant's viewpoint, (4) the conduct of inquiry in a way that limits disruption of the natural context of the phenomena of interest, (5) acknowledged participation of the researcher in the research, and (6) the conveyance of an understanding of phenomena by reporting in a literary style rich with participant commentaries (p.15).

These common characteristics were operationalized through out the research design, collection, analysis, and presentation of findings. A description of how these characteristics were used in the research is included in the following section.

Maintaining the Qualitative Paradigm

The first characteristic is the belief in multiple realities. As well, the researcher "makes no attempt to place experimental controls on the phenomenon being studied or to control the 'extraneous' variables" (Morse & Field, 1995, p. 10). A belief in multiple realities describes the researcher's understanding and acceptance that the experiences of the participants are represented by their own interpretation. Therefore, what one family member experiences and interprets may be entirely different than another family member's experience and interpretation. This does not mean the information is incorrect

but that the experiences and interpretation of events are unique to the individual. The potential ambiguity and variations of the data will be accepted as the truth from the family member. There was an understanding from the beginning that there was not one truth or one way of interpreting the first hospital admission for a family member.

The second characteristic was a commitment to identifying an approach to understanding that supports the phenomenon being studied. Although the interview questions had already been determined and were based on the literature review and crisis theory; however, the researcher was unsure of the possible responses. "The semistructured interview is used when the researcher knows most of the questions to ask but cannot predict the answer" (Morse & Field, 1995, p. 94). Exploring the needs of an individual during a first hospitalization was best facilitated with open-ended questions and a semi-structured interview process. The researcher further confirmed this method by consulting with a support group facilitator. The facilitator reported this method would be appropriate and accepted by the individuals in the support group as it allowed for significant disclosure and consideration of privacy issues.

The third characteristic was a commitment to the participant's viewpoint. Semi-structured interviews were used to engage family members in a discussion of their experiences of a first hospitalization. The interview included open-ended questions that gave participants latitude to speak of their experiences (Streubert & Carpenter, 1999). This is consistent with exploratory research. It also included open-ended questions to address the features of the experience through the lens of crisis theory. The literature review also aided in maintaining the focus on the participant's viewpoint as literature of

family members' perspectives was reviewed in preparation for the research. A specific

needs assessment format was purposely rejected so as to minimize superimposing a pre-

determined outline of the interview and again maintaining the focus on the participant's

view point.

The fourth characteristic was to conduct research so as to minimize the disruption

of the natural context of interest. The interviews occurred in the home of the family

member (a natural setting) or another place of their choice. "If participants are removed

from their setting, it leads to contrived findings that are out of context" (Creswell, 1998).

The researcher did not attempt to influence the perceptions of the participants and

attempted to remain neutral during the interviews. This was done to ensure the

perceptions of the participants were not disrupted by the interview process.

The fifth characteristic is recognition of the researcher as participant. The

experience of the researcher and other aspects of the researcher were part of the study.

The researcher brought her experiences to the study in the research design and data

interpretation. The researcher had spent approximately five years working at a Crisis

Stabilization Unit and implementing crisis theory as an assessment and intervention

method. The communication skills and interview techniques used to work with families

and clients in a mental health care setting were used and influenced how the interviews

were conducted for the research. A journal was kept by the researcher to help organize

thoughts and ideas and lengthy discussions were held with her advisor to monitor the

implications of the researcher as part of the study. The preliminary findings were also

shared with many colleagues and friends working in health care. These discussions aided

in a 'verbal exploration' of the results and further aided in understanding the context of the information. One of the major influences identified was the lack of experience of the researcher as this was the first qualitative study completed. However, this novice perspective may have aided in maintaining the researcher's role and involvement as an "active learner who can tell the story from the participants' view rather than as an "expert" who passes judgment on participants" (Creswell, 1998, p.18).

Finally, the last characteristic of the qualitative paradigm was that the study's findings were reported using many rich descriptions in a literary style consistent with qualitative research. "The general goal in qualitative writing is to present the data so that the reader shares the participants' experiences" (Morse & Field, 1995, p. 174). The results section of this research project was completed using appropriately edited quotes with supporting paragraphs to allow the quote to supplement the text (Morse & Field, 1995). This was purposeful and was thought to provide a purer representation of the participants' experiences. Each participant was introduced and a section of the interview was included to give context to their experience. This was also considered a respectful gesture to the participants who spent so much of their time and energy sharing their stories with the researcher.

Participants

Recruiting family members and caregivers is a common method identified by many researchers in this area (Corring, 2002; Doornbos, 2002; Lukens, Thorning, & Lohrer, 2002). Participants were primarily recruited from a support group of family members whose family member had been diagnosed with a mental illness. One of the

support group facilitators was consulted on many design features and feasibility of this research study; she acted as a recruiter for the study participants by providing the support group members with a letter of invitation (Appendix C) from the researcher during a support group meeting, and included the invitation in a monthly newsletter to the support group members. This was done to ensure the participants met the criteria and, similar to ethnographic research, the recruiter could be considered a gatekeeper. A gatekeeper is "an individual who is a member of or has insider status with a cultural group" (Creswell, 1998, p. 117). The cultural group in this situation was the support group. The participants were asked in the letter of invitation to contact the researcher by phone; however, most of them provided their name and number to the recruiter instead, with instructions to pass the information to the researcher. The researcher then contacted the individuals by phone to ensure they met the criteria, to explain the project further, and to set up an appointment for an interview.

There are many strengths and limitations of interviewing one family member compared to multiple family members (May, 1989) and these must be considered carefully in any research design.The practice of involving one family member in family-related research is practical and consistent with other researchers who have examined the family's needs in mental health (Levine & Ligenza, 2002; Wallace, Robertson, Millar and Frisch, 1999). Hatfield, Gearon & Coursey (1996) had individual family members complete a survey of mental health services to "gain an overview of families' needs and burdens and the perceived value of several services" (p. 826). However, the researcher in this current study does not presume the needs of the entire family can be determined from

the needs identified from one family member. Interviewing a family member was done to simplify and focus the organization of the data (Creswell, 1998). Interviewing an entire family as a unit would uncover data much more dynamic, involving siblings and parents of varying ages, potentially causing further confusion in answering the research questions. The research questions focused on family member and were developed as a beginning point so that further studies could potentially build on the data, perhaps including entire family units at a later date, which is consistent with a more inductive process of inquiry (Streubert & Carpenter, 1999). Robinson (1995) agrees and argues that there are risks in examining the whole without consideration of the individual or parts which make up the whole. The parts of the whole need to be examined first to ensure the perspectives of family members are adequately explored and fully accounted.

Definition of family member.

For the purpose of this study a 'family member' was broadly conceptualized. At the inception of the research plan, it was anticipated that the best individual to be interviewed would typically be the individual who was most involved in the hospital experience. That 'family member' could potentially be a spouse, an adult child, or a friend involved in caregiving activities, but since they were accompanying someone to the hospital it was assumed that a relationship of significance existed. It was also assumed that that family member continued to provide some level of care after the hospitalization. These assumptions were part of the inclusion criteria for the participants and were reviewed prior to the interview. A definition was therefore adapted and modified from Levine & Leginza (2002), who also conceptualized the family member similarly.

Therefore, a family member was any individual who self identified as an unpaid

individual providing some level of care and support, on an ongoing basis (Levine &

Leginza, 2002), for an adult who has had at least one hospital admission for mental health

care in Winnipeg.

Purposive sampling strategies.

Purposive sampling is "a type of nonprobability sampling method in which the

researcher selects subjects for the study on the basis of personal judgment about which

ones will be most representative or productive" (Polit & Hungler, 1995, p. 650). These

methods were employed to identify the most appropriate "participants who can best

inform the research according to the theoretical requirements of the study" (Morse &

Field, 1995, p. 80). The family members had all experienced the same event of having

another family member hospitalized in mental health. The participants, with the

exception of two, had all been in contact with a support group to varying degrees. One

member had actually participated in starting a support group, while another participant

had attended only one meeting. The support group had been in existence for

approximately four years and its membership fluctuated frequently. Family members met

the inclusion criteria to participate in the study. A snowball effect of soliciting further

participants was employed at the end of each interview by giving an invitation to

participate in the study (Appendix C) to the family member; this was, however, largely

unsuccessful. Attempts were also made to interview the spouses of the family members,

but were also unsuccessful.

Data Collection

Semi-structured interviews were used to gather the data (Appendix A). Some

minor alterations to the interviews were expected as the researcher gained experience

with the interview process and the data were collected. As certain similarities developed

from one participant to the next, the researcher made notes and was able to seek

clarification in subsequent interviews. The participants were interviewed for

approximately 1-2 hours in their home or chosen location. A total of 10 interviews were

completed and saturation was suspected after 6 interviews. This type of exploratory study

of a specific event may be judged as adequate after 10 interviews (Sandelowski, 1995).

Field notes were used to help identify the thoughts and hypotheses of the researcher and

to organize possible questions or areas in need of further questioning.

Basic demographic data were collected with the help of the researcher at the start

of the interview (Appendix B). In hind-sight, the collection of the demographic

information did little to inform the data analysis, although it provided an opportunity to

become comfortable in the interview process and to develop rapport with the participant.

Rigor

In qualitative research, methods which ensure the reliability and validity of the

research data subsequently strengthen the conclusions and are important design

considerations. Lincoln and Guba (1985) describe four aspects of rigor (or what they

refer to as trustworthiness) as credibility, transferability, dependability, and

confirmability. These were constantly considered in the research design, data analysis

and discussion of the findings.

Credibility involves determining whether or not the data collected and interpreted are true. Credibility means questioning if the findings are accurate. Strategies to achieve credibility include member checks, peer debriefing, audit trails and prolonged engagement (Tobin & Begley, 2004). Several different methods were implemented to ensure the credibility of the data. Prolonged engagement with the participants meant meeting with the participants prior to conducting the interviews and then checking back with the family members at later dates throughout the analysis. The interviews ranged from 45 minutes to 90 minutes and were audiotaped. "Since a major criticism of qualitative research methods is the issue of systematic bias during either data collection or interpretation, audiotaping of data sets is an appropriate step since it allows auditability of data collection procedures" (May, 1989, p. 179). A random selection of two to four family members was initially planned to verify the conclusions as part of the data analysis. Since the process of contacting family members was most validating and informative to the researcher and the participants, all family members, who had previously consented, were contacted. Family members were contacted by phone and detailed notes were taken as a verbal summary of the results was provided. Family members were then sent a summary by mail. Participants were invited to contact the researcher at any time they felt information had been misinterpreted. Throughout this process, the researcher met with an advisor (an experienced researcher) and maintained an audit trail. Several mental health professionals were also consulted informally on various findings, for further discussion.

Transferability refers to "whether the findings can be applied to other contexts or settings or with other groups" (Morse and Field, 1995, p. 143). The participants in this research study shared many homogenous characterisitics. The majority were educated at the university level, married and working full time. The participants all came from a similar socioeconomic status. With the exception of two, they were all affiliated with a support group to varying degrees. They all had experienced a son or daughter who required an admission to a mental health care setting in the last four years. It is highly conceivable that their experiences are not unique and the conclusions developed from the data would be relevant for other family members with similar characteristics in similar circumstances. During many informal discussions with family members external to this research project, when themes or issues were discussed, family members have enthusiastically confirmed that their own experiences were similar. Also, comparable themes are cited in related research (see Chapter 5) as well as similar recommendations which suggest the findings will have resonance for others in related situations.

Dependability refers to the ability of the data to remain consistent over time. The interviews were all completed in a four month block. A year later the participants were contacted by phone to confirm the analysis of the data and conclusions. A rigorous process was followed in determining the themes in the study. This process was recorded and an audit trail was maintained to provide a method to review the process of data analysis and determined how decisions were made throughout the analysis. An advisor who is an expert researcher was consulted throughout this process and provided with transcripts and other material illustrating the systematic method.

Confirmability is the objectivity of the data or the extent to which two separate individuals would come to a similar conclusion. Confirmability was also maintained through the use of a systematic method. The process was well recorded and, as previously stated, an expert researcher monitored the progress. Transcripts were read and the interpretation of the content was continually discussed by the researcher and the advisor. Key informants were also used to verify the conclusions. This process is further explained in the data analysis.

Data Analysis

The data were transcribed by the researcher to further immerse the researcher in the data and to allow the researcher to 'relive' the experience of the interview. The researcher had great difficulty completing this task due to several problems with the recording quality of the tapes. A transcriber was hired to complete some of the interviews which slowed the process of data analysis but did not appear to effect the understanding of the data. Blocks of time, often for a full week at a time, were set aside to complete the in-depth analysis of the data.

Morse and Field (1995) described four processes which appear to be consistent throughout most qualitative methods. These processes are comprehending, synthesizing, theorizing, and recontextualizing. These processes were followed in an attempt to be systematic in content analysis. Essentially, data collection and analysis occurred concurrently so that, as the similarities emerged, they could be further explored in subsequent interviews. This occurred in a minor way as the researcher was a novice to collecting qualitative research data. There were many similarities noted and recorded

during the interviews; there were, however, few specific themes. The researcher spent time thinking about the interviews, the family members' experiences/stories, and possible themes, as well as discussing them with an expert researcher and other colleagues.

Specific categories or preliminary themes were identified when the transcripts were read and re-read while listening to the interview tapes. This was completed to grasp the subtle nonverbal methods of communication which are not 'observable' in a transcript, such as emphasis, and provided a much deeper understanding (Burns & Grove, 1995). This was done in a block of uninterrupted time until the researcher felt the understanding of the interview data had been reached and another level of examining could begin (comprehending).

The interviews were again re read for the purpose of identifying important topics or themes. Notes were made in an attempt to organize the information and highlighters were used to color code similarities within and between the transcripts. After these similarities had been identified, continued reading of the transcripts was done to ensure the meaning of the interview data was appropriately identified and led to 'cutting and pasting' the specific highlighted sections into separate word processing files by color codes (synthesizing).

The separate files were read and re read to determine if the quotes were truly indicative of one theme or several themes, and whether the quote accurately illustrated the theme. The 'cut and pasted' quotes were then compared again with the transcripts to ensure they were accurately interpreted and not taken out of context. Some themes were then combined or renamed (theorizing).

Finally, the data were analyzed for patterns and relationships between the categories and the extent that the data fit with the conceptual framework (recontextualizing). This involved many discussions with a key informant and a secondary discussion with eight of the participants. A diagrammatic representation of the data was developed based on the conceptual framework (see Chapter 5).

Ethical Considerations

Ethical considerations were made through consulting the principles outlined in the Tri-Council Working Group's report on the (DRAFT) Code of Conduct for Research Involving Humans (1996). Furthermore, a proposal for the research was submitted and approved by the University of Manitoba, Education/Nursing Research Ethics Board. Ethical considerations included establishing an informed consent process to meet the requirement for free and informed consent, methods were developed to maintain confidentiality and anonymity of the family members interviewed and their families, and data collection methods were considered to ensure the protection of participants from risks.

All participants read or had read to them a letter of consent which clearly stated the purpose of the research. If there was verbal agreement to participate, the participants signed the consent form and were provided with a copy (Appendix D). The informed consent clearly stated that the participant could stop the interview at any time.

Confidentiality was explained in the letter of consent, before and after the interviews were conducted. The participants were instructed to maintain confidentiality by not using their family member's name during the discussion. However, this became

difficult and almost unnatural during the interviews where the participants were speaking so intimately therefore it was quickly discontinued. Names did not appear on the transcriptions. Participants also had the option of withdrawing from the study at any point. All participants in the interviews were identified by the date of the interview on their demographic information sheet and in the transcription of the audio tapes. No names were used on the typed transcript. All data (transcripts, tapes, demographic data, etc.) were stored in a locked storage container at the University of Manitoba, Faculty of Nursing and will be kept for 10 years prior to being shredded or discarded as confidential waste.

The interviews required a commitment of one to two hours and the interviews were held at the participants' location of request. Every effort was made to ensure the convenience of the interviews. There were no anticipated risks to the participants or to a third party. In the event that a family member experienced difficulty following the interview, the member was supplied with a phone number and name of a Registered Psychiatric Nurse trained in working with families and Critical Incident Stress debriefing. Contact with the Registered Psychiatric Nurse was strictly confidential and she was not connected to the research in any way.

There was no deception involved in this study. All essential information was made available to the participants. Feedback was provided by the researcher if there was information which required clarification. The final analysis was made available to the participants upon request.

Conclusion

Chapter three described the research design and methodology. Every effort was made to ensure that all possible variables were considered. The methodology represented a 'recipe' for structuring the research and was essential to maintaining the overall credibility of the researcher and of the resulting conclusions.

Chapter Four: Results

The overall intent of this research was to uncover the needs of the family during a crisis period, through the exploration of the experience of a family member. The first four research questions were explored and clearly answered throughout the results of chapter four. These questions included:

1. What was the perception of the event by family members during the crisis period of the first hospitalization?

2. What were the available support systems for family members during the crisis period of the first hospitalization?

3. What were the coping mechanisms used by family members during the crisis period of the first hospitalization?

4. What were the family member's needs during the crisis period of the first hospitalization?

This chapter starts by presenting the demographic information collected from the participants of the study. Each participant was then introduced, along with a corresponding pseudonym, and an excerpt from the transcripts which illustrated the types of experiences the participants related leading up to the hospitalization. The experiences leading to the hospitalizations were not the focus of the research, but were clearly important to the participants and usually represented a lengthy portion of the interview. The interview questions were not specific to this period of their experience yet in the interviews it naturally became the place to start. Furthermore, these experiences were

necessary to place the hospitalization experience in context and formed a much deeper understanding of the research findings.

The chapter was then separated into three sections which included perceptions of the event, situational supports and coping mechanisms. In the current study, the perception of the event was simply how the family members appraised and reported their feelings and experiences within the context of the hospitalization, and was therefore labeled Perception of the Hospitalization. The major themes of this study were all subsumed under the Perception of the Hospitalization which addressed the first research question. They included:

- feeling **relief**,

- feeling **disbelief and shock**,

- feeling the **ripple effect of the hospitalization/diagnosis**,

- feeling **alone and stigma**,

- feeling **excluded during discharge**, and

- feeling **grief/loss** as their expectations for the future changed.

Situational supports were considered separately from the perception of the hospitalization; the situational supports portion answered the second research question. Many of those interviewed offered suggestions for the type of supports they would like to have received, which also addressed the fourth research question. This section helped to identify who and what the family members felt was supportive. Coping Mechanisms was the last area explored with the participants and addressed the third research question. Family members described a wide range of coping mechanisms they employed during

the hospitalization and especially during the time of diagnosis. Again, this did not develop into themes, however the data were categorized into **problem focused** and **emotion focused** methods of coping.

Demographics

Ten individuals were interviewed for their perspectives on the first hospitalization. All met the inclusion criteria in that they were at least 18 years old, identified themselves as being a caregiver or family member, had a family member admitted to a hospital in Winnipeg in the last 4 years for the first time, and the hospital admission was in the Mental Health Program. There was representation from all mental health care facilities in Winnipeg.

Participants were asked to complete one page of questions prior to commencing the interview (Appendix B). In most cases the interviewer completed the form on their behalf. There were eight questions surrounding demographic information, represented in Table 1. All participants identified the individual they would be speaking about as their son or daughter and therefore that information was not included in the table.

Table 1. Demographic Representation of Participants.

Participants	Does your son/daughter live with you?	Length of Stay during first hospitalization	Age	Employment	Status	Sex	Education
1. Shelley	Yes, sometimes	More than 28 days	50-59	Part-time	Married	Female	University Degree
2. Carolyn	Yes, all the time	15-28 days	50-59	Full time	Single	Female	Some Post-Secondary
3. Jane	Yes, all the time	More than 28 days	40-49	Full time	Married	Female	University Degree
4. Susan	No	7-14 days	40-49	Full time	Divorced	Female	University Degree
5. Linda	Yes, all the time	More than 28 days	50-59	Full time	Married	Female	University Degree
6. Darlene	No	15-28	40-49	Full time	Married	Female	University Degree
7. Karen	Yes, all the time	More than 28 days	40-49	Part time	Married	Female	Grade 12
8. Robert	Yes, all the time	More than 28 days	50-59	Full time	Married	Male	University Degree
9. Laurel	Yes, all the time	More than 28 days	50-59	Unemployed	Married	Female	Grade 12
10. Becky	Yes, all the time	7-14 days	40-49	Full time	Separated	Female	University Degree

Introduction of Participants

Each person interviewed gave a lengthy detailed description of events leading up to the hospitalization. This was often described as being a very difficult and chaotic time. Although the focus of the interviews was on the hospitalization period, there was a real urge on the part of the families to discuss the experience leading up to the admission and it placed the hospital experience in context. Most family members described feeling that they were in a crisis prior to hospitalization. Family members often related trying to convince their family member to go to the hospital after having witnessed unusual and

sometimes upsetting behavior for days or even months at a time. The following represents only a fraction of these examples that the family members discussed in the interviews. This part of the result section also provides an opportunity to introduce the participants on a personal level.

Participant #1 was given the name of Shelley. Shelley was the first person to be interviewed. As illustrated by the previous demographic table, her son was the family member affected by mental illness. Although Shelley was used to speaking about her experiences at a local support group, this interview was very different because the focus was on her personal feelings and perceptions. At one point during the interview she became very emotional and stated she was surprised by her own expression of feelings since it had been some time since the first admission. At times during the interview it was difficult for her to separate her own feelings from those of her son in her descriptions of experiences, and the interviewer had to redirect to maintain the focus. Later on in other interviews this was found to be frequently the case. Shelley's story leading up to the first hospitalization, like all the other participants, was one of chaos and involved a lengthy portion of the interview. In this excerpt she described the experience of working with the psychiatrist to convince her son to accept an admission to hospital. The psychiatrist evidently did not want to admit him involuntarily and there was a shortage of beds in their area.

> A: It was extremely stressful. And dramatic. For my husband and my son. Circumstances were that [my son] was off his medication for a period of time and his doctor had been away on vacation... phoning every day... to see how he was coping. Um. And when she returned, ... took my son to see her and , um, she, at that point, said you must be hospitalized. Um. You're not safe to yourself. And, um, and he did not want to go into the hospital, um, so his dad and I sat with him

and the doctor for over an hour trying to persuade him. At that point he still was not willing and, and she did not want to, uh, admit him….

Q: Involuntarily?

A: Involuntarily. So she said, I have another appointment. Go for coffee. Come back in an hour. … but then I really don't know how long she would have done that. But she was going … you're going to do this on your own, these are the benefits … So that's was we did do … he finally said, I don't have a choice obviously. And she said, well yes you do. Well I don't but, um, the end result was she'd also been phoning to see where a bed was available and discovered that there were no beds anywhere in [one facility] and [another facility] had the only available bed which was very, very distressing to all of us because there was a lot of stigma attached.

Later Shelley returned in the interview to discuss her own state of mind at the point of

admission.

No, that's not our normal family. Like I'm, I'm just, you know, wired and shaking and just beside myself because I've just spent the last few hours …and arguing with him and pleading with him and his doctor. The one doctor, his doctor, the doctor from the hospital and all these people phoning and my son listening and saying, I'm not going. And again and again and again. And you've done that for 8 hours. And then you finally get him there. And you're ready to collapse.

Participant #2 was given the name of Carolyn. Carolyn was a single parent of

three children all in their late teens to early twenties. Carolyn was the second interview to

be completed. Her experience with her son was preceded by the knowledge that

something was wrong but that 'something' was not understood until one day the situation

became potentially dangerous.

A: OK. Well what happened, I was at my girlfriend's house and I got a phone call from my son, C, who's a year and a half older than J. saying that J. had a knife in his hand and he was saying really stupid stuff and that something was wrong. So I said, OK, I'll be right home. So took me about half an hour I got home. It must have been about 11 o'clock at night I'm guessing and … pretty late. And so I got home and there was J. the knife in his hand, and so then I said to C. what's wrong, like what's happening. And I had been feeling there's something, something was wrong.

Q: Right.

A: We had known something had been wrong for a while but we didn't know what it was now. Now this was like, you know, and so anyway, he'd heard there was people coming and he had to defend us. So I knew that we didn't have to be worried. He wasn't going to hurt C. or me. So that was a good thing. But then it was a matter of getting knife off of him. And, and getting him to the hospital, you know... So I had no problem. And he agreed... You know this knife thing isn't good and, you know, you're going to have to come to the hospital. So...

Q: And you knew to take him to the hospital? Or that was your first thought?

A: Oh yea because I was scared. I was scared he'd stab. So I thought, yea, what else would I do. I mean I knew that this wasn't a police thing, you know, because he had had... an appointment to see a psychiatrist who knew there was something wrong. But then it takes so long. And so he went to his, at this point a pediatrician, And his pediatrician had made an appointment for a psychiatrist But it was like, two and a half months later which wasn't helping us.

Later, once Carolyn was able to bring her son to emergency, she talked about her experience in that department which seemed equally difficult for her emotionally.

In Emerg and then we had to wait. So then he got to see a doctor and then, of course, we had to wait for the Psych consult. And so it was two more hours. And we were just really lucky because we got Dr. F. Yea, he's just a wonderful, wonderful psychiatrist. And, and he told me, he said later, the reason he came, personally ... was because... [when] he gets a phone call that the kid's waving knives around, he thinks psychosis right away so he wanted to be the one to come into see J. ... I got to be in the interview... J. tried by himself at first and then I got to..., come into the interview after that. And that was very good. But it was like, it was this really, really overwhelmed. I think because he, because he said that he, J. was in psychosis and, of course, I didn't know what psychosis was. So then he was saying something about out of reality and all that kind of stuff and, and then he said, and then at one point he mentioned, uh, schizophrenia. ...So at that point he lost me because... it was bad. Like that's bad. And then he's saying that I want J. ... to go home. And I'm going, Oh no. Like oh he shouldn't go home. Because I'm scared. I'm thinking, like what's going to happen now. ... I have to worry about my other kids. My son and my daughter. And , you know, so I didn't know what to think. But he, he said like there were no beds for starters.

Participant #3 was given the name of Jane. She and her husband, participant #8 were the only couple interviewed although they were interviewed separately and the data

from the interviews were treated separately. Jane had previous experience working in health care and worked full time with three children in their late teens to early twenties. She explained the situation leading to her son's first hospitalization in the following excerpt.

> So from there we took him to our family doctor who treated him for depression. And also he was very uncomfortable in social situations. Like he couldn't finish up his summer job. Couldn't, he was like having social anxiety. Just couldn't be around other people. And he became more and more introverted and kind of stayed in the basement, did a lot of journaling. And I think he became delusional but I didn't realize it at the time. He'd make a joke of it, say, well I'm going through.... And C. has a very dry sense of humour and we kind of laughed about it. But now, you know what, he was serious. He was delusional, you know. But I didn't, we didn't quite get that at the time. And, um, and the family practitioner treated him for depression, um, he became mad. Just really mad. Totally bizarre. He was at university at the time and I said, oh, did you go to your class. He said, he'd say no which is very unlike him. Was really responsible. So what did you do? I walked around the campus and I stopped people and I talked... Mmm. OK. Which concerned us because it sort of made him kind of vulnerable.

Participant #4 was given the name of Susan. A divorced professional, she was the only one who did not have her family member currently living with her. Her son had left the province to pursue other endeavors. At the time of hospitalization, her son and daughter had been living with her while they attended University. Susan spent a long period trying to manage her son and his psychotic episodes in her home and as a result missed a significant amount of work. During the time leading up to the hospitalization she was trying to recover from surgery and deal with her son's psychotic episodes which seemed to escalate at night. She spoke with a soft voice and did not always provide explicit detail however, the way in which she spoke conveyed volumes of her emotional experience.

...Then he started going downhill again. You can kind of see that he was having these periods of distress and periods of... And he... just really scary at times... And there were a couple instances where I just felt like I had tried every trick in my bag and I wasn't getting to him or I wasn't reaching him. And it was like, he's slipping into this darkness and I couldn't stop it and pull it out and it was just the scariest thing...

....

...This was all leading up to that hospitalization and then ...sort of almost daily crisis episodes and some were worse than others. And they were, and no point in this time was, was settled that you felt like, you know, things were under control.

Participant #5 was given the name of Linda. She was one of only two interviews which occurred at her place of work instead of her home due to the number of teenage children she had at home. At the time of the hospitalization, her daughter was living with several roommates. Today Linda's daughter lives with the family of origin. Linda explained that her daughter seemed to manage better with more structure and family support. She described in detail the day her daughter's roommate called to say something was wrong and that somebody had better come and see her. Linda and her two other daughters went to see what was wrong.

...And she was making no sense. She was talking about picking things up off the street and she's got this red, um, she called a pill, candy. Red candy. She picked up this red candy off the street. And I put it in her mouth and she was just making strange stories up like that and talking about, um, kind of nonsensical stuff. Start something, stop, and then kind of look all over the place. And her eyes would just be going every which way. And I said, you know what S., I think you need help. I feel ...I don't know how to handle you

Participant #6 was Darlene. This interview was very different from the others because Darlene's son committed suicide. Her teenage son was suffering from undiagnosed depression at the time of the first hospitalization. Darlene briefly discussed

the scene leading up to the hospitalization as her youngest son approached her early one

morning.

> He said, there's a problem. Something's wrong with A. I said, what's wrong?
> Come downstairs and you'll see. And he was just in a very agitated hyper state.
> Um. I would say, are you all right? And he said, yes I'm fine. I said, what kind of
> drugs did you take at the party? And he said, right, I didn't have anything. I just, I
> smoked some marijuana a couple of days ago. And I said, well A., that doesn't
> explain your behaviour now. Do you think maybe somebody slipped something
> into your drink. No, just a couple of beers. Did you, do you think maybe
> somebody slipped something into your drink. And he said, well mom, it's all on
> the hockey schedule, can't you see? It's all on the hockey schedule. So I thought,
> OK, I said, go get dressed. And we're taking you to the hospital.

Participant #7 was given the name of Karen. This interview took place in a

public area, about which the interviewer expressed concern because of the sensitivity of

the topic and need for confidentiality. However, Karen stated she preferred to meet at the

local coffee shop since her husband was recovering from surgery. The interview went

very well despite the location.

> A: And what we were getting very concerned about is the fact that he was
> withdrawing and withdrawing and withdrawing. And he seemed to spend so much
> time with pen and paper in hand and scribbling. And we look over and see what
> he was scribbling and there was nothing really that made sense or will make it, it
> just didn't make sense. But our biggest concern was is that he had trouble
> communicating verbally with us. So after a period of some time of sitting down.
> And I told my husband before. I said, you know, we really should take him to the
> hospital. Something's going on.

Participant #8 was Robert who requested that his interview occur at his place of

work. Despite the fact that he was the only male participant, his experience was expressed

similarly to the other family members interviewed.

> There were some issues in terms of working in the school division. [My son]
> worked there ... very conscientious. But there were some issues about him, the

speed of his working and he was complaining about working with people, just didn't feel comfortable around working people which was kind of odd. And so we just noticed something. In September he went to university, University of Manitoba. And was in University 1 and he was and he was coming home with these bizarre stories. He was just walking around the university and he'd say, he'd be talking to people all day. Wouldn't go to class. And he'd talk about these really interesting conversations he had. And initially it was, you know, you just thought well it's maybe a phase or something but it didn't go away and then I think it was in October. It's like a nightmare.

Participant #9 was Laurel. She and her son had been involved with child mental health programs and thus she was one of the few participants who knew of her child's diagnosis prior to hospitalization.

Those meds didn't, weren't doing what they should have been doing. And things just started falling apart. And we were on holidays in, um, July, we were down East visiting my daughter and he started having hallucinations and, um, just, you know, really bad thoughts and stuff. And we came home and then, of course, they get into that cycle where they think, you know, that that's not a good med, the doctor's not any good, he doesn't know what he's talking about. And things started just going downhill and, um,

...

...he was very suspicious of Dr. He didn't like Dr. A. He just, from the time he started going to him. Maybe if he'd been with Dr. B., he really liked him. And Dr. B. could relate to him. But it, um, it just wasn't. He just couldn't persuade him to take it. And then he got depressed and, you know, he tried to give him an anti-depressant and he wouldn't take that. And, but it was just a constant phoning the doctor, trying to go to the doctor, getting to the doctor. And things just started spiralling out of control.

Participant #10 was given the name Becky. Becky was in the midst of dealing with her son's second admission to hospital at the time of the interview and the diagnosis was as yet unknown. She had recently become separated from her second husband and her main supports (her family) lived in another country. Becky described her son's thoughts and how confused she felt upon hearing them.

And he said that he thought that my ex-husband and I, like he's his dad, not the most recent one. But his dad and I had been conspiring with people where he worked and everybody out in the world more or less to follow him around to make him feel bad, to send him messages and to harm him. So when I heard that, I wasn't quite sure what to do or where to go.

Perception of Hospitalization

Relief

Relief was the first theme and represented the initial appraisal of the situation by the family member. For there to be relief there must be something from which to experience relief. The relief was from situations of chaos and crisis that generally led families to the emergency rooms. To know that the chaos was going to be addressed by health care professionals provided an initial sense of relief. Relief was also identified once the son or daughter was finally admitted and was equated with their son or daughter being safe. It constituted a feeling and conveyed an expectation that things were going to be fixed or at least there was help in situations where family members often described feeling helpless. All but one family member described or expressed varying degrees of relief with the initial hospitalization of their son or daughter.

Linda provided an exemplary example of relief. Her statement described her feelings about the initial hospitalization of her daughter.

> Actually I felt, she's in the place she needed to be. I can't help her. I don't know how to help her but I know I'm in the place where she will get help. Cause I didn't know where to go or what services were available.

Laurel also described her relief upon admission and included the impact of the

events had on her physically and emotionally. The advent of hospitalization represented a

personal break from the worry.

> Oh God. Did I want to leave him there? Yes, in some ways...it's like you know
> he's not safe at home. And something had to be done. Something had to be done.
> We were getting to the end of our, our. Physically just even, for me, just... I mean,
> you know, not sleeping. I'd spend hours in his room rubbing his back or his feet
> because he couldn't sleep. Couldn't get to sleep at all and I'd just spend hours
> doing that. Just laying on the floor beside him, you know.

The one individual who did not express any sense of relief had a relative with a

diagnosis of schizophrenia and she explains this in the following excerpt.

> How did it feel? Uh. It was devastating. It was, um, oh my God. Because my
> husband has a brother who has schizophrenia. And I, I guess because none of the
> other siblings, they all had their children, nobody had schizophrenia. And to be
> honest, I'd be very human and say I felt cheated. I felt really cheated. And I also
> felt like our son had been cheated.
> ...
> I had my suspicions and I, and I suspected. And I kept praying that, oh God
> please, please don't let it be like, like my husband's brother D. Um. Because his
> was a sad case. And I equated one with the other.

No doubt the hospitalization represented a confirmation or at least the possibility that her

son may also suffer the same fate and may explain why she did not state she felt any relief

as did the others. It was her knowledge and awareness of schizophrenia that kept her

from feeling relief.

Disbelief and Shock

All participants, who did not know of their son's or daughter's diagnosis prior to

admission, described a time when they were faced with the seriousness of the situation.

This occurred during the first hospital admission and often coincided with the receipt of a

diagnosis. At this point the initial relief appears to have vanished and was replaced with shock and disbelief. As the parents continued to re-appraise their situation, the seriousness of the situation, the actual setting and/or the reality of the diagnoses resulted in an emotional reaction.

Disbelief or shock was commonly surrounded by description of family members feeling they were in a fog or the moment was a blur as they struggled to grasp the reality of what they were being told. This fog was almost a paradox since the participants also pointed out that this was a very significant time and often details were unusually clear.

Robert tried to describe, during the interview, what it felt like to hear of his son's diagnosis.

> I'd say, like somebody once described being black Monday…because it's… like getting your arm caught in a car door, it's just, it's a shock and it's like after a while, it's like, you just don't notice. Just becomes a blur. And, um, it was worst time of my life.

Jane describes the moment she was told of her son's diagnosis. She had difficulty in comprehending what she was being told and yet felt she really had not understood the reality of the situation.

> Well that day that I think that I was told he had psychotic illness. The ramifications that really hit me. …I cried for two weeks. … the doctor … he did tell me about the disorder at that time. But, I needed to hear it. We didn't hear it. Not that day.

Karen attempted to clarify the paradox between the fog of the moment and lucidity about the details of the story. This part of her story was so emotional and very descriptive it had a lasting effect on the interviewer. Karen described disbelief for her as being a detachment from reality.

... probably like what anybody says, you know where you're walking.... But it's, it's like, this is not happening. This is not happening. You open the door and you get out of the elevator and you get into that locked unit.

...

... And I think one of the, uh, trying to recall. This is real foggy in this area. I'd have to think on that. Have to think on that. Um. All I remember is the process was very, uh, confusing to us because you have to appreciate the other thing is, is, we're already dealing with them being sick. So your ability to really think things through and understand is not there. ...when you're not in the situation and you're looking and you see someone else in it, it's very clear. But when you're in the middle of this, you're like in a great big soupy fog.

...

And we went to walk out the door and I'll never forget the sound of that door shutting. Very gentle touch and this little click indicating he's locked, he's locked in. My baby.
You don't forget. Like I don't forget the day my children were born...

Other family members described disbelief by expressing the sense that their child did not "belong" in the hospital setting; often because of the physical surroundings or presentation of other patients.

Shelley described her feelings about the facility and her discomfort of leaving her son there.

And a facility that in no way was welcoming or warm or comforting. And this thing, leaving my son in a place where when I walked into [the facility] there were people yelling and screaming and states of disarray and very sick.

Carolyn also described her discomfort of her son being admitted to a mental health unit.

It was too, the hard core things... probably be too hard core for him. It just wasn't him and... he didn't need to be exposed to that I think.

Finally, Darlene provided her thoughts on seeing a mental health unit for the first time and asked the attending psychiatrist why her son was being placed there. The response set the stage for a turbulent relationship between the family and psychiatrist.

I mean I wasn't really thinking anything because I was still shocked. And... to see all these people mulling around. Like there was Alzheimer pat..., most of the people that I saw were elderly, talking to themselves, muttering to themselves.

....

... I said, what kind of ward is this? I said, I see elderly people and, and there's women here and... he very succinctly, maybe put sarcastically or whatever in brackets, said, well madam there is no such institution made exclusively for 19-year-old suicidal males. This is it. You don't want him here, take him out.

The three families who did know the diagnosis prior to admission did not describe the same stories of shock and disbelief following relief after admission. However, the shock and disbelief they experienced when their son or daughter was initially diagnosed did surface in the interviews. It was clearly a significant time in their lives prior to the initial hospitalization, as illustrated by Laurel's recollection of receiving her son's diagnosis:

> It never goes out of your mind. It's just like, can't get rid of it. It's just, you know, a lot of, oh why didn't I, why couldn't we, why shouldn't we, why haven't we, why, you know, why, why, whys. Why didn't he. But there's no mental illness in my family so it was absolutely something that just flew out of the sky at us and not something we'd ever had to deal with.

Shelley, who knew her son's diagnosis, reflected how difficult the hospitalization would have been had she not known of her son's diagnosis.

> And that's just because I'd already done the research and I had the information, but if I didn't know the information, having had information, having that understanding how the illness works, knew what to expect, and you knew the medication, and you knew the side effects. Again I'm really really big in understanding and the education. The education for the family and that piece I knew. If I hadn't had that then I think I would have been even more beside myself and... there's so much stigma attached to mental illness, even more so. And you also just don't know what's going to happen. Like you just sort of poof, you know, like one day it would be fine, the next day he wouldn't talk to us.

Disbelief represented the second major theme extracted from the interviews and

was the result of continued appraisal of the family members' situation shortly after admission. Disbelief and shock was universal as described by family members during the first hospitalization, with the exception of those who had already received a diagnosis. Disbelief was often described as being in a fog or a blur; however, family members explained there were very clear circumstances during that same time which they still recall years later. The next theme was less clear in terms of the order of events but was described by every participant at varying places in their hospital experience.

Feeling Alone

All participants talked about feeling alone or isolated. It was almost subtle at times during the interview but a sentiment which seemed clear to the interviewer after each interaction with a family member. Family members often described feeling alone because of the difficult situation they were faced with at the time of hospitalization. Many felt they were the only one to have experienced their situation, adding to the exclusivity and fostering feelings of being alone.

Carolyn described her feelings of aloneness, which she attributed to her son's illness rather than to the fact that she was a single parent.

> You think that nobody else could ever experience it so, yea, so you don't even have the feeling of that there's other people out there.
> …What happens is… all of a sudden nothing becomes important any more. It was just like, you're just, you're immersed into this new thing and it's like, and it's so different and there's a lot of stuff that you just, so strange. So when you meet other people that have experienced it, it's like, wow, it's like being home. It's such a nice feeling.

Susan illustrated her experience using the metaphor of being in a black hole.

> … it was, it was those times when you just felt like you needed help and nothing's, nothing available... And nobody to know really who has gone through

this, you don't know who to call or anything like that.

…

Like very superficial interactions with them, like they're living in the house and having crisis on a nightly basis that you have to deal with it on your own…

…

Just felt like being in a black hole with him…

Feelings of being alone were also illustrated when family members talked about a lack of understanding from others, particularly from family and friends. Linda also used a metaphor for her family's experience of feeling alone and excused her friends for not understanding or being incapable of supporting the family during this difficult time.

> And most of our friends didn't understand it. Lord knows we didn't so it was hard for them. They stayed away because they didn't know what to say. Yea, so it's like, OK, here we are on this little island and we're all floating, we're going to drown real soon.

Feeling alone during this difficult time was universal for the participants. For some family members it motivated them to start a support group, the same support group used to access at least half of the participants in this study. The participants still described feelings of being alone in their circumstances, but described accessing support groups to alleviate their isolation. Feeling alone was not exclusive to the hospitalization period however; it appeared to start there and continue after discharge. Feeling alone was further complicated by the stigma that all family members discussed therefore, stigma is considered a sub theme of feeling alone.

Stigma.

All participants mentioned some form of stigma or secret in relation to the hospitalization experience and how they were negatively affected by the stigmatization of mental illness. Often this meant the diagnosis or hospitalization of the son or daughter

was not shared with other family or friends, which greatly contributed to their feelings of

aloneness. Stigma was experienced even from the health care professionals.

Laurel, like so many other parents, described the experience of waiting in

emergency with a son who was experiencing psychosis and being constantly moved aside

for seemingly more urgent physical cases to be addressed by the emergency room staff.

She described feeling as though her and her son's suffering was not as important as those

who presented with more evident physical suffering or trauma. The message that was

perceived by the family waiting to be cared for was that mental illness or their pain was

not as serious or important.

> Like you go in there and there's this person suffering hugely and you're put down. We knew every time we'd just go down the ladder… we'd see somebody come in with a heart attack and we'd do, oh my God, we're never gonna, you know, that was our attitude… a sliver would have gone ahead of us…. Well, I'm sorry, but we're in crisis now and he needs help now…. but to be sort of just left sitting there… sitting there. Sitting there hours. Hours. I've sat, we all, we sat hours and hours, I can't tell you how may times we sat there in the middle of the night.

Carolyn tried to explain her experience with stigma and having to deal with her

son's request not to tell other people about his illness. However, this was not the only

reason why she chose not to tell other people, and she explained that other friends and

family may not have been capable of understanding her situation.

> … J. was very worried that he didn't want me telling people. Because he didn't want people thinking that… he was different and all that kind of stuff
>
> …
>
> … it's not just that person being in crisis but the family's being in crisis because this is all bizarre and so we're living in this house that's very bizarre and nobody else knows about it and so it's almost like this big secret… and that's really hard. So you, feel a stigma.

Susan tried to explain how she balanced seeking support for herself from family and friends and still respect the wishes of her son not to tell people about his illness or hospitalization.

> ... you select who you think will be understanding and not judgmental. Uh. You want to respect his privacy, you know, like it's not something that if, that happened to me, I'd want my family sharing with everybody they knew, you know.

There are many implications and challenges for family members when the son or daughter requested individuals to be excluded from knowing of their illness or hospitalizations. Even more difficult was when siblings were kept from being told of the hospitalization. Not being permitted to share the information greatly contributed to the family members feeling alone in their situation.

Stigma was also described in the way family members framed the information that had been given within their own beliefs about mental illness. For example, Susan discussed her own beliefs of mental illness as being related to popular media images of mental illness.

> ....But still, you're not even completely... completely sure on what psychosis really is. I'd heard of it but I'd never seen it. Except for, you know, people that, you know, are really over the deep end and... like living on the street.

Linda discussed feeling personally responsible for her daughter's illness and further felt uncomfortable leaving her daughter on a mental health unit because of the stigma.

> It was just really hard to leave your child in a psychiatric ward. Like it's sort of like, it's that mental illness thing. Oh my God, I've really screwed up with this child, you know, like what have I done wrong.

At times during the interview family members discussed the advocacy they were

involved in as a result of the mental illness in their family and the stigmatization they felt

or experienced from others. Linda described her thoughts on mental illness and how she

chose to address the stigma.

> ...Do you read stuff about this in the paper? No, it's almost like oh, hush, hush,
> don't talk about this. And... like I do talk to some people about mental illness
> now because I think it shouldn't be hush hush. It's an illness. These people are
> sick and they need your help and support. If we all run away from it and hide, it
> will never change.

Some family member's even described being stigmatized by health care

professionals themselves. Carolyn described her experience while her son was admitted.

> So the stigma's the big thing and sometimes you think that the people in the
> hospital are somehow worse people for the stigma. ... sometimes I wonder... why
> are you working here... because... sometimes, you get the feeling it's like they're
> always whispering. It's like, this is reality. This is reality for us so, I mean, you
> don't have to whisper about it. This is real. And you know what I mean?

Similarly, Shelley described her son's request not to tell his own siblings about his

admission to hospital.

> I think one other thing that came to mind was that, for my son, there was so much
> stigma attached to [the hospital] and being in [the hospital], when we took him
> there, that first night, and he said, I do not want you to tell anyone that I am here.
> No one. And he said, well what about your brother and sister? And he said, no
> one.
> ...
> ... And we said, this is going to be very, very difficult. ... And he said no one.
> And it was like, oh my goodness, how can we do this? Um, you know, siblings...

Stigma was described and experienced to varying degrees by all family members

interviewed. Stigma presented a barrier to accessing support from family and friends and

forming relationships with other health care professionals. What was even more

disconcerting were stories that siblings were unaware of the situation, possibly having

many implications for trust, support, and overall family dynamics. Stigma was very

powerful with the ability to either silence some people or, conversely, to motivate other

individuals to challenge the misinterpretations of mental illness in our society.

Feeling the Ripple Effect

The ripple effect described the impact and changes that occurred throughout the

rest of the family as a result of the hospitalization and subsequent diagnosis. Every

member of the family was described as having to change or adjust as a reaction to the

diagnosis. Family members described these effects as fear and uncertainty which caused

significant changes in the relationship between the siblings. The family members

interviewed described trying to compensate and assist in the adjustment between their son

or daughter and their other children. Descriptions of the impact of hospitalization on

families and the individual members existed in every interview.

The impact of learning the diagnosis and the first hospitalization resonated with

families for a long time. Families described the impact starting in the hospital or even

before and continuing sometimes for years, especially as siblings grew in maturity and

were able to comprehend the meaning of mental illness more fully. These stories were

not conveyed positively, often highlighting the negative impact on the family or

individual siblings.

Linda described the impact her daughter's behaviour and diagnosis had on every

single member of the family after her daughter had to move back home after the first

hospitalization.

> A: So we, we just basically let her do what she wanted to do. Tried, everybody
> tried to stay clear of her. Walked on eggshells around her. So it was not the

happiest household. It affected every single one of the kids in different ways. And I think they will all have that lasting effect on their lives I really do. Um. But they were all extremely close. They still are very close but cautious around their sister now. Still to this day.

Q: Two years after the fact?

A: Well because she had another episode....

The kids kind of... got very involved in everything. Everything. It's like every minute of her [other sibling] day had to be busy. I said you don't have to do that. But that was her coping mechanism.

...

A: Our oldest son, he was kind of busy with his friends then too but he, being a little bit older, was very, he was careful with us too. Like he had more of a caring attitude with us too. Not all the time but sometimes. The youngest was probably the one we worried most about. He has learning problems and [S.]... was very, very kind with him always. Still is. Always very kind to him. ... and so he had a real loss. So we worried a lot about him and, um, for him I got the counsellor. He was at the school. So I had the counsellor get involved with him and talk to him kind of on an ongoing basis. ... so, and the two of us [family member and spouse], I don't know. Somehow we got through it.

Jane's experience also showed the impact on all the siblings and how it affected each one differently. She highlighted how parents struggled to come to terms with the situation themselves and yet felt they needed to be available for their children who were also struggling. Trying to compensate and meet the needs of siblings combined with their own personal needs as parents was clearly overwhelming. Jane started with her son's reaction to his brother's [C] illness.

And, um, being so close to C. was devastating. And it just kind of pushed him over the edge in terms of, he was an angry young man. I think because he thought he contributed to it, and he just winged out. Left home. Got into drugs. So this followed shortly after. And now, in hindsight, and at the time, you know, you've been punched once and then you're punched a second time. And you're really angry. And then you're really angry that two of your three children have mental illnesses. And I, I don't think we saw clearly that what had happened to C. had such a huge effect on him... later we did. And then my daughter was 13, 12. She's a child. She thought like a child. She just couldn't understand why her big brother wasn't exercising any more. And why did he start smoking, you know, and he'd sit her down and he'd say, it's an illness. She did not get it.

...

... You can't see the illness, if it was a broken arm in a cast, maybe. But it was not concrete and she, yea, and she was awful, uh, in terms of kind of yipping after C. and saying, why are you smoking... Giving him a hard time, you know. And fighting with E. so. But with L. it evolved, uh, she's 18 now. She was just about, yea, 13 when it happened. But the evolution with her was interesting because as she got a bit older, as she could understand more, then we almost had to kind of retell the stories to her... As she... [could] understand more then we would give her more information. And, uh, she didn't want to hear it and she did not want me to tell any of her friends. She said, you know, hide it under the rug. And, uh, she's come a long way. She's come a long way.

Many family members stated how profound the experience was on the whole family. To further complicate the experience family members often stated how difficult it was that, from their perspectives, the health care team did not recognize the implications for the family. For some the impact of the illness began long before the hospitalization. Shelley discussed her experience and perspective.

Like you're coming in there the most vulnerable... as a family. You've been under tremendous stress for either, you know, weeks or months or you've had some days from hell. And it's absolutely unravelled and you get to the point of... because you're going in as a family and individuals of the family, very, very vulnerable and very, very frail. ... I could remember going in and hearing... and I can remember the hospitalization feeling so frail and I'm certainly... uncomfortable going into [the facility], uh, but so just being shaky, like just feeling shaky... So I think to have the, the validation of somebody saying, how are you? How are you doing? Uh. And not that they can solve any of this.

Feeling Excluded - Discharge

Most family members relayed the story about the discharge although there were no specific questions included in the interview which addressed the discharge process. The discharge represented a difficult time for the family and the common theme during the discharge portion of the hospital experience was the perception that family members were excluded by the health care team. Even when a family meeting was held prior to or

at discharge, the family members described the experience as one that they were invited

to but had little opportunity in which to be active participants. Other family members

described difficulty with the discharge process or reported that a plan appeared to be non-

existent at discharge.

Several family members talked about the health care team having a 'plan' for their

son or daughter while little input from the family was sought or desired.

Linda, a school teacher, likened the experience of a discharge meeting to the meetings

which were held in her own work environment. Certain words have been underlined to

show the emphasis on Linda's perception of lack of involvement and ultimate exclusion.

> So we finally got a little bit of information and then the day that she was actually
> released, we had a big review. Like nurses and the doctors and oh there were.
> Now I know how parents feel when they come to schools and there's like six of us
> and two of them. That was kind of what it was. Six of them and two of us.
> ....
> And so we were all there and we could ask questions at that point. S. found that
> extremely hard. It was very, very hard on her… They decided to release her at that
> point. She was nowhere near well. But they decided Outpatient would work. And
> they had her on heavy, heavy medication and she basically slept.

No one ever clarified or stated 'you are being excluded' but the perception of

many parents was that they did not have a say in the decision and were ultimately

excluded. Similarly, Susan attended a discharge meeting. As a health care professional

herself she was still passively excluded from the discharge planning meeting even though

she was in attendance.

> A:There was a team meeting before he was discharged.
> Q: OK. Was that supportive?
> A: It didn't, it didn't feel like it at the time. But I suppose that's what it was
> designed to do.
> …
> A: It felt more like, this is our plan. Our plan is to discharge him and, you know,

like it wasn't, it wasn't joint decision. It was like, he's going to get discharged. What do we need to talk about before it happens. And I, you know, I didn't. There were concerns. Like it was a place to air concerns but it wasn't a place that decisions were going to be changed or anything you know. I was, at that point I was relatively happy to have him in the hospital. And relatively concerned about him coming home.

Darlene's experience showed exclusion from the decision-making process but when she did ask for guidance or assistance with the transition home she was not provided with information.

> A: You know what… there was no story. There was just, I guess he had a couple of passes, day passes and then sleep-over passes. And they just said, he's going home. I said, well what am I supposed to do? And they said, I don't know. I'll just tell you that he's a very high risk for re-attempting. I said, OK, so why are you letting him go? Well he handled all his passes well. And I thought, OK.
> Q: So how did you feel bringing him home?
> A: I was terrified. I was terrified. I felt, he received absolutely no therapy in the hospital whatsoever.

In some of the situations described there was little communication between the family and the health care professionals, which compounded the perception that nothing was being done for their son or daughter and that there were no plans for discharge. Becky's experience illustrated this perception of the discharge.

> He was discharged after a week and a half because he didn't want to be there any more. Now, I don't think they'd done a proper assessment. And there was no real, there's a big family meeting at the end when he was going to be discharged. So I went, my husband at the time went, his brother went and D. was there. And then there was the doctor, a social worker, and the nurse. And D. There wasn't anything really mentioned in terms of community supports or what happens once you've left and there's a reoccurrence. There was no information given in terms of, this is D.'s treatment plan, this is when you want to make sure that he follows it. And absolutely none of it. There was, I don't think there was a treatment plan. I don't think there was an assessment done. I think he'd seen a doctor for maybe 45 minutes and that was it in a week and a half. And so he was discharged with a prescription for really low dose of Risperadone. And given a follow-up appointment. He didn't go to that appointment because he forgot.

The discharge stories of the participants and their perceptions of the experience exemplified being excluded. Even when gestures were made to include the parents, the perception remained that the family members were not full participants and were ultimately excluded from the decision making process. What was even more disconcerting was that when health care professionals were sought by the parents for information, they did not respond. Sometimes family members described poor communication between the health care professionals. Overall, there was a lack of understanding of the discharge process.

Loss and Grief of Changing Expectations

As family members continued to appraise their situation during the hospitalization and started to understand their son or daughter's diagnosis, they all described feelings of loss and grief. Because the interviews were a retrospective account, sometimes up to four years after the hospitalization, it is difficult to determine if this actually began to surface during the hospital stay. However, several participants indicated this was something they started to consider during the initial hospitalization. A change in the expectations of their son's or daughter's life path and expectations of what their son or daughter would accomplish were heavily surrounded by expressions of grief and loss and the unknown at the time of diagnosis.

Loss was specifically identified by Shelley as she realized the implications of her son's diagnosis.

> ...here's a bright handsome, uh, young man at 17 who's world is his oyster and the staff acknowledges. This could be pretty devastating for the parents. The loss potentially of all the dreams for your children and what would that mean for this

child and... I will always worry, what will happen to him when I die

Jane described the change in expectations occurred on the day she was informed

about her son's diagnosis. Like many parents they described the stages of grief.

> Well I could see myself moving through stages of loss. Huge loss. Uh, I couldn't look at his... graduation picture for a year. I put it away. This is gone, which turned out not to be true. ...Anger. I don't think I stayed in denial much because that day it hit me and I, I had adjusted that he had an illness...

Robert explained how he had come to terms with the change in expectations and

how he has now adjusted to measure his son's successes differently.

> That's really what it is because it's, you're losing, you're losing the person that you had. You're gaining something, you're gaining someone who's, who's a little different. You've lost the person, the expectations, the athletic guy, the pretty good marks, you know, he's got a future. So you're not only losing the person's personality in a way, you're losing your dreams. You're losing your dreams of where he will be of having a normal life and having a family and of grandchildren, you know. And, uh, and you're grieving for him because he will, you're grieving for yourself but also grieving for them because you know that they realize or they will realize that, that they, that their lives will be different.
> ...
> He's probably going to be with us a long time but I foresee him, like he's getting better. Like we measure success, I mean it's making my, being better at this job in that I measure success differently with everybody. Success, success is in the eye of the beholder. Success is, uh, in the milestone where he can go to Safeway with one of us.

Some parents were more pragmatic and expressed feeling loss because their son

or daughter could not complete simple tasks that had previously been taken for granted.

Similarly to Robert and other parents, Linda described celebrating new types of successes

and milestones. Linda talked about having to change even small expectations of her

daughter because she could no longer complete tasks such as loading the dishwasher.

> It was like S., just do it. Just pick up the dishes. Just take it over there, you know, it's not a big deal. I think that all those social skills, all those little things that she had been taught, it's like do they have to go... in the dishwasher. No. Didn't

know. ... all the things that you take for granted that you trained your kids to do were non existent. But she was living under our roof again... now they're all coming back. And when I go home from work now and she's made the salad for dinner and she's picking up the tea towel... and went... it's OK. But it's nice... when you live it, it's nice to see the change.

Karen provided a very matter of fact interview; however, towards the end she

became very emotional, as did most of the parents, during this part of the interview.

I, um, ... coming home at night so we had to deal with the idea that he was suicidal. And we pretty, pretty quickly learned that if you're gonna be of any help to him, you're just going to have to learn to deal with things in a very different way. And what you expect from him and from what is going to have a change.
Q: What sorts of things changed?
A: Um. Just the goal that he wouldn't be sleeping so much.
Q: As opposed to?
A: To watching him go from his bed to the couch to wherever and just, to get him to go outside at one point during the day for a walk or the fact that he actually was, didn't pace for 20 minutes or, you know, just a lot of different things, very small things... You measure success in different ways. The fact that he would get up and get dressed is, was a major coup.
...
A: The fact that you could get him to brush his teeth every couple of days.
...
A: Shaved once a week. And not just, you know, a part of his face, missing the other.
...
A: Your ideas of success are. You're remoulded, you're totally remoulded . You have and you learn to accept the fact that whatever dreams you had for your son, they're gone. They will never happen.

Parents grieved the loss of everything from their son or daughter's personality to

the ability of their son or daughter to put dishes in the dishwasher. Regardless, this area

within the interviews was the most emotional for the family members. It was also clear

that everyone was at different stages of acceptance. Becky was the one parent who did

not express loss or grief. Although this was not explored during her interview, one

variable which might explain her lack of grief was that her son did not yet have a formal

diagnosis. Loss and grief were not usually identified by the other participants until there was some realization of a diagnosis and it became 'confirmed' that their son or daughter had a mental illness.

Situational Supports

Through the course of the interview, the participants were asked varying forms of the following questions: "What were some supportive aspects you experienced the first time your mentally ill relative was hospitalized?", "Which supports were most helpful?", and/or "What got you through the event?" (see Appendix A). A definition of support was never offered nor was one asked for by the participants. The responses varied but fell into one of two categories. Many family members identified their own family as either supportive or not supportive. Secondly, family members identified that the act of accessing information was supportive. Accessing information was often in the form of a support group, the internet, or a formal counselor. The support families sought had more to do with seeking support in dealing with the diagnosis rather than the hospitalization itself.

Many family members stated their own immediate family was supportive. Linda highlighted the fact that there were few people in her life to turn to for support and therefore she relied heavily on her spouse.

> So I think, no, there was nobody we went to. Nobody we talked to. We totally relied on each other. Um. I had some close friends who I talked to. And that helped.

As previously stated many family members accessed sources of information for support. These sources were often people as opposed to a book or written material on

mental illness. Darlene, shortly after her son's hospitalization accessed a familiar family

counsellor.

> For emotional support.... And it's not the kind of thing that you, um, you're under
> so much stress, you're not going to go through the phone book and look through
> counselling services. Or, or I shouldn't. We did, um, there was a family counsellor
> that J. and I had been to before because he'd been there with his family. So J.
> knew him and said, how about if we go to this counsellor. And we did see him
> and we took the boys with us. I asked A. if he wanted to come. He refused. But
> the 4 of us went...

Karen was connected with the Manitoba Schizophrenia Society during the first

hospitalization. She identified this as helpful but felt she needed the information sooner.

> I remember the admission. ...Plus we did have a session with somebody, I'm
> trying to think of her name, and actually she was on the board of directors at
> Manitoba Schizophrenia Society. And her giving us their package. But it was like,
> um, I felt it could have been sooner than later.

Susan also talked about attending an educational program which she reported as

supportive and helpful, but also identified the need to have the information sooner - even

during the crisis stage of the hospitalization.

> well that program... eventually I could go [to] a 8-week program through the
> Schizophrenia Society... I forget what it's called but it was a really difficult...
> Like I would, I felt like I learned so much. Like I...information that I needed it
> really quickly. Like even at that stage of crisis...

Carolyn explained why the support group she accessed provided her with the

support she needed at the time of her son's hospitalization.

> Well I cannot say enough about the family group. Like they were, they were, they
> were just excellent. And it was like you're just the same. What happens is... all of
> a sudden nothing becomes important any more. It was just like... you're
> immersed into this new thing and it's like, and it's so different and there's a lot of
> stuff that you just, so strange. So when you meet other people that have

experienced it, it's like, wow, it's like being home. It's such a nice feeling. And so, and this group was so great because you exchanged phone numbers.

When specifically asked about the supportive aspects of the hospitalization, most family members were very clear about their thoughts on the support offered by the hospital. The responses were surprisingly similar and the tone during the interview was that of negativity. The responses were short and it was difficult to encourage elaboration on the topic. The simple response was usually 'Nothing' followed by silence. 'Nothing' was meant to be all inclusive of the question. The following are examples of the dialogue during this portion of the interview.

Q: Tell me, what were some of the supportive aspects that you experienced during that time?
A: From the hospital? Nothing.

Q: Were there any supportive aspects during that hospitalization?
A: No. None. Nobody ever said, how are you guys doing? Do you need help? Does your family need help? Do your kids need help? Nothing. No, nothing.

Q: Can you think of some of the supportive aspects that you experienced the first time he was in the hospital there at the [facility]? Was there anything that you thought was really helpful?
A: No.
Q: No?
A: No.

Robert and Carolyn both tried to explain why the hospital was not supportive.

Robert suggested that perhaps he and his family were not open or ready for the support and therefore support was not perceived.

And I'm not sure if we were ready for support. I don't, like I don't know... when you have your hand slammed in the door...you need some time to deal with the nerves to kind of come back so you can feel the pain...

Carolyn explained she did not perceive the staff as being supportive because they did not approach her.

> Q: Were there any supportive aspects of that first hospitalization? ...
> A: Uh, not that I'm aware of.
> Q: OK. You didn't find any, anything?
> A: No. I mean... you could talk. And, because I like to ask questions. They would answer my questions and stuff. But it wasn't like they were coming and saying, you know, like what can we do for you. That never happened. That never happened

What is clear is that the hospital staff was not viewed as offering support to the family members. Family members were left to seek support from family, friends, and external sources of information. Almost all family members had suggestions to improve the support from the hospital staff for family members. In fact, they were more interested and enthusiastic in making suggestions than discussing their own experience in the hospital setting as family members.

Shelley highlighted some of the things she felt would be supportive in the hospital setting.

> ...I think it would be so helpful for somebody just to get your child settled in.
> ....in their approach. Just that calmness to calm not only my son but to calm me
> ...
> ...That kind of solid, concrete helpful information where you can talk to the psychiatrist, you can talk to the team, you can ask the questions of other family members who have been through this. Like that sounds or makes so much sense.
> ...
> It's very important for you to look after yourself or you're not going to be able to look after your son or anyone else in your family if you're not doing that self care. And that acknowledgement by staff, again, could, could really be very, very helpful.

Carolyn described her feelings and recommended having time and contact with staff for educational purposes, which would have fulfilled her supportive needs at the time of hospitalization.

> But I mean like somebody should be telling you these kind of things, you know. And… there should be, like good education. Not just throwing a book at you. They should sit down and say, OK, you know, this is what's going to happen. This is, and they should say, this is a hallucination. This is what delusion is. Shouldn't have to try and read it because when I was reading that book, it was like, to me, all it was was so negative and so, um, so scary and so cruel that I was having trouble reading it. I needed someone to tell me. I wouldn't need to read it. I needed to have like a person actually sit down with me and talk to me about it.

Darlene talked about wanting to be involved and how that would have been supportive for her and her family.

> Family involvement and have family meetings. Again, I think I said before that a person doesn't live in a vacuum and I think it's extremely important, um, to get the entire picture because I don't think patients can always be reliable to tell the absolute truth.

Laurel, who knew of her son's diagnosis prior to the first hospitalization, described how she accessed her sister, who happened to work in health care, during her time of needing support.

> So I would access her at all hours… poor woman, I'm telling you. … I'd phone her. So she'd jump in her car and she lives in St. Vital and she'd drive over here. And we'd sit. Sometimes he'd disappear on me and I remember it was the Olympics were on one night. It was just starting. And she came over here and sat with me until, oh I was in a crying jag. And, you know, I just, I couldn't quit crying. It was the middle of the night. He's gone. Where in the hell is he. I would cry all night. And I, sometimes you just so totally lose it, right. And she came over and sat with me… gave me a drink and she… tried to find some pills for me. I don't, I don't have Valium. I don't have sleeping pills, I don't have anything. And, uh, she sat here and he comes home. He walks in here, 4 o'clock in the morning, you know. Like nothing's wrong. And we're sitting.

Susan's suggestion was to have a central place to attend where everything there was to know about the mental health programs and supports would be available. For her, trying to navigate the available resources was a considerable source of stress and having the information made readily accessible would have been supportive.

> I think I would like to have easy access for people in our, you know, like myself coming in to this mental health world. Where you could go somewhere and... there's all the information. One spot. I can get everything I want, you know. I don't have to go here, there, everywhere. At the time it was like there was nothing. I mean you'd try and find something.

Becky was clear with her recommendations and had a unique position in that her son was admitted for only the second time to hospital and had yet to receive a diagnosis. Becky constantly contrasted the different experiences she had had between two separate facilities. The first facility refused to see her son after discharge because he had missed his follow-up appointment. Becky had called and asked about the time and date of the appointment so she could facilitate her son's attendance but was told due to confidentiality, she could not be given the information.

> A: Yea, being included. And if I'm the caregiver... you want to keep an eye on what's going on so you can be there to support that person and make sure they get to appointments on time and know what you have to do and just knowing what is expected from the news like this. If it has peaks and valleys or, you know, those kinds of things. And just being included and the information and being kept up to date with any kind of treatment plan. Just the courtesy of being able to talk to somebody, you know.
> Q: Did you say that the staff were approachable at the [facility]? Like you said they were friendly.
> A: Oh yea. They were approachable but they didn't approach me and say, um, I'm D.'s nurse for tonight. At [another facility] they did. I'm D.'s nurse for the day. I'm D.'s nurse for the night and seems he's been doing OK or he tried to escape today or such.
> ....
> A: I think I would just like to have known the whole process, what they're going to do while he's in there. How long he may be in there or if they can even tell you

that right now. Just to know that they can't tell you how long he's going to be in there. And talk about voluntary or involuntary and what that means. They're going to know from talking to me for a little while but there are some serious issues there... and needed some kind of therapy or medication or...whatever.

What was viewed as supportive by one individual was not necessarily viewed as supportive by another person. Support may be highly individualized although in the case of hospitalization the family members interviewed agreed that the hospital staff were not supportive during that time. They did however have some suggestions for providing support. These suggestions often seemed to involve not only having contact with the hospital staff in a way that allowed the opportunity for their own thoughts and feelings to be expressed, but also for the opportunity for education to occur. It had been suggested that perhaps some family members in this acute phase had difficulty receiving support because of the crisis or the seriousness of the situation. However, it was also stated by more than one family member that the need for information, quickly and at the time of crisis, was essential to feel supported.

<div align="center">Coping</div>

Aguilera (1998) cited Coleman's (1950) definition of coping as "an adjustive reaction made in response to actual or imagined stress in order to maintain psychological integrity" (p. 38). This definition is broad and reflective of the way it was conceptualized by the interviewer during the interviews. Coping mechanisms are recognized as highly individualized and are based on the past experiences individuals have had in coping with stressful situations. However, a definition was not provided to the participants when they were asked "What did you do to cope with the experience of the first hospitalization?", and the participants did not request clarification. As family members appraised their

current situation, during the hospitalization period, they chose coping mechanisms based on their perceptions of the situation. Family members identified a number of different methods they used to cope with the hospitalization period. The different methods were categorized into two sections. **Problem focused** methods of coping included actively doing something, seeking information, or caring for themselves. **Emotion focused** methods included escaping from their situation, substance use or expressing emotions.

Problem Focused

Actively seeking information was also identified by more than one family member as a method of coping. Linda and Karen provided the following quotes respectively.

> But when it does, like we're the kind of people that, OK, what's out there, what's available. ... how can we learn, what do we need to learn and then what can we do to help her.

> Especially for a parent of well, for the type of parent I am. I don't say every parent is like this, we all deal in different ways. Um. For me, I educate myself on what I'm dealing with. Give me a name and I can deal. That speaks specifically to me.

Several family members spoke specifically about recognizing the need to care for oneself. Shelley talked about her feelings and recognizing when things were starting to become overwhelming and what she did to cope with the situation.

> ...I go for counselling because as I said, like I've listened, um, I'm losing myself, I'm losing my ability to, to be whole, to function, to look after my family, to, uh, to even realize that I'm not OK, you know. I'm not looking after my family and myself... And when you, you can get to that point, you know, you go, oh, it's time to take a step back and say, what is it... medication, whether it's exercise, whether it's good friends. ... with somebody saying, what are you doing to look after yourself. It's very important for you to look after yourself or you're not going to be able to look after your son or anyone else in your family if you're not doing that self care.

Becoming physical was considered a problem focused method of coping and often involved walking or aerobics. For example, Becky described her method of coping, which highlighted social factors, supportive factors, and a strong emotional factor, in the following interaction.

> A: ... And I exercise.
> Q: Oh do you?
> A: I go, I haven't been but, that's why... I've gone back to my exercise. I used to go back and cry. Sometimes I wouldn't make it. And some of the ladies that I go to, I've known for years. So they would bundle me up and put me back in my car and send me home.
> ...
> Q: What do you like to do? You run or do you walk?
> A: No. I go to, I go to aerobics. I go to, it's this class but I know everybody. It's just in the community clubs over here. I go 4 times a week and
> Q: Good for you.
> A: it was, it's probably the, something that just has really helped me. I'd say that anyway. Just calms me and gets rid of all that stress.
> Q: Do you get a chance to talk too?
> A: I can. And know, and there's quite a few of them who know what's going on. Not everybody but most of the, you know, that I would trust...

Most family members described 'doing' something to cope with the situation. 'Doing' involved actively seeking out an activity. Darlene described her method of coping as cooking and pointed out the cultural factors which influenced her choice of coping mechanism.

> I cooked a lot... You've obviously never interviewed a Jewish or Ukrainian mother. Or Italian mother, you know, food is the centre of everything. And to me it was comfort. And I, at that point I loved to cook and it was just around the Jewish New Year so I, there was a lot going on and I had made a lot of his favourite food. And, um, so we're taking them just trying, I guess, to comfort him. To show our love, you know. And, um, and in a very, very I guess, not conscious but probably subconscious level thinking that look how much we love you.

Linda talked about the way in which she and her husband spent extra time with their other children.

So we actually, we've always done a lot with them and we always made a point of, like if they're playing volleyball, we're there. Play basketball, we're there... So always made a point of doing that. But we kind of doubled it up. We tried to do it even more. We tried to do some family things together. Once they get to be teenagers, lord knows they don't want us.

Emotion Focused

Escaping the situation attended to the emotional needs of the family members.

Several family members described methods of coping where they chose to hide away

from reality often to regroup or take a break. Often escape was described as going to

work where things were "normal". Laurel quickly identified her method of coping

> .... I was working too and sometimes that's kind of nice to get away and kind of forget, try and forget about it for a while.

Carolyn described how she coped by escaping.

> So what was really good for me was that just kind of thing, you don't really talk to a bunch of people about too because of the acute stigma. I mean you feel a stigma right away, you know that that's, you know. And, um, so work really helped. So I, I went to work and nobody at work knew what was going on. So it was like a real kind of normal place to be. And I was spending, you know, my 8 hours a day there and so that helped me because it was a sense of, uh, being normal and everything under control there.

Some family members admitted to using substances such as nicotine or alcohol to

help them cope with their situation. Others accessed health care professionals for anti-

depressants. These were also considered ways of coping through escaping. Jane was very

open and expressed her need to increase her anti-depressants and the time off work.

> And I am a smoker, sure I smoke more. I upped my anti-depressants cause I've had a history of clinical depression for 10 years. And, uh, I always take anti-depressants... and my doctor would vary the dose up and down so it definitely went up...

And, uh, then I ended up injuring my back and being off work, which I'm sure was a way of dealing with stress... I stayed off a while. I probably could have gone back to work sooner.

Carolyn made a conscious decision to find ways of coping, which included drinking. Although trying to be humorous during the interview, she really communicated the extent of her desperation in a very difficult situation.

...At one point I thought, I should try drinking. Because I knew this would help. Because it's painful. And I thought maybe I'll start, like I'll be an alcoholic and, you know, that'll be something else but it'll make me feel better.

Becky like many of the others described more than one method of coping. Here she also pointed out how much more difficult it was to incorporate her known coping mechanisms when she was spending a lot of her time visiting her son in the hospital.

Q: ....We've talked about ways of coping.
A: Oh yea.
Q: You pointed to your cigarettes.
A: And I have an extra glass of wine.
Q: Extra glass of wine.
A: Wine. Yea. That works. I tried, I try to see D. as often as I can which usually means every day unless there's something else on. So I haven't been out here, exercise as much as I like. So I try and, I've been out for a walk whenever I can. I used to do a lot of exercise. I used to do aerobics and do karate. Walk the dog. I don't have a dog to walk anymore.

Finally, the coping method most identified by individuals as a way of coping was crying; however, other emotional methods were mentioned. Karen described the emotions she felt during the first hospitalization which were tied to denial of the reality.

A: Because at that point, for myself anyway, I felt like a small child. I didn't feel like a grown-up, uh, and I didn't want to act or be a grown-up. I wanted to...

[start] screaming and carrying on. I did not want to endure this.
Q: That's one way of coping
A: I didn't. No. I, I just, I wanted to refuse to accept it, you know.

Susan was brief in her description but was clear about her coping methods during the

hospitalization.

Cry. Lose sleep. Cry and lose sleep.

Shelley described how she would cope with the hospitalization experience.

I'd cry.... I'd drop him off at 9 o'clock at night. I'd pick him up at 3:30 on my
way up to Gimli or up to the beach and we'd walk along the beach together and
we'd go for dinner and... the doors closed at 9 so we would get back right at 9
o'clock and go in and it would be dark and I'd... drive home... I would have the
radio on and I'd cry all the way home.

Various methods were used to cope with the hospitalization experience and they

were highly individualized; however, there were commonalities and categorization of the

coping mechanisms was possible. Overall, family members coped with the experience by

actively doing something, escaping from their situation, being physical, and/or expressing

emotions. These represent two larger categories of coping, which include problem

focused coping and emotion focused coping.

Chapter Five: Discussion

The discussion starts by revisiting the conceptual framework. A diagrammatic representation of the current research results was developed to explain how the conceptual framework was used to organize and interpret the data. After reviewing the results within the context of the conceptual framework, a natural progression to the recommendations follows. This discussion section focuses on the implications and recommendations of the study to health care professionals. It is important to note that there were strong intentions on the part of the researcher to ensure that this research was practical and held direct clinical relevance. It addresses the answers to the final two research questions for this study, which includes: 'What were the family members' needs during the crisis period of the first hospitalization?' and 'What can health care providers do to address the needs of family members during the crisis period of the first hospitalization?' Relevant literature is integrated where similarities in findings or recommendations were found. Finally, the chapter is concluded by brief recommendations for further research and the identification of limitations of the study.

Application of Framework to Current Study

A diagrammatic representation was developed based on the results of the current study and the framework provided by Aguilera (1998) (see Figure 2). The top of the diagram represents the time prior to hospitalization. As families experienced events, such as observing symptoms of psychosis or other unusual behaviors, family members had a difficult time adapting to the situation and entered a state of disequilibrium. Since they could not reestablish equilibrium on their own, family members were motivated to obtain professional assistance for their son or daughter. This led to hospitalization. Once

the son or daughter was hospitalized, the family members used their appraisal of the

ongoing situation and available resources to gain a new equilibrium. These experiences

were explored in the current study through interviews designed with consideration of the

three balancing factors as outlined by Aguilera (1998). The factors that helped balance

the disequilibrium included Perception of the Event, Situational Supports, and Coping

Mechanisms. In the current study, the perception of the event was considered the family

members' appraised and reported feelings and experiences within the context of the

hospitalization, and is therefore labeled Perception of the Hospitalization. The major

themes of this study were all subsumed under the Perception of the Hospitalization. They

included:

- feeling relief,

- feeling disbelief and shock,

- feeling alone,

- feeling stigma,

- feeling the ripple effect of the hospitalization/diagnosis,

- feeling excluded during discharge, and

- feeling grief/loss as their expectations for the future changed.

The extent to which family members reported realistic or unrealistic perceptions had the

ability to affect how well family members were able to adjust to the experience. Family

members were not evaluated for their level of functioning or ability to adjust to their

previous experience of hospitalization in a retrospective interview. This level of analysis

was not completed as the intent of the research questions included open exploration of

the event. It would be difficult to judge or measure to what degree family members

reported realistic or unrealistic perceptions of the event. Similarly, situational supports and coping mechanisms were identified. Situational supports included family, friends, and support group(s). Coping Mechanisms were divided into problem-focused and emotion-focused. As with the perception of the hospitalization, these balancing factors were not evaluated for adequacy nor were judgments made about their usage. Indeed, their perception was their reality. Perceptions are developed out of appraisals of a situation. At the point of hospitalization, the family members constantly appraised and re-appraised their situation. In essence, they were trying to determine what the situation meant for themselves, their family member, and their family. This appraisal and reappraisal phenomenon was described by Lazarus and Folkman (1984) and used in the original explanation and development of Aguilera and Messick's (1986) conceptualization of crisis theory.

Not surprisingly, the themes identified in the current study are mainly affective or emotional in nature. Lazarus and Folkman (1984) explained that the "emotional response is in fact specific to appraised meanings" (p. 53) and may be identified more readily in appraisals than specific cognitive thought processes. Appraisals have been identified as primary, secondary, and reappraisal. Primary appraisal is the determination that a specific event is "irrelevant, benign-positive, or stressful" (Lazarus and Folkman, 1984, p. 53). Secondary appraisal occurs when the individual tries to determine what can be done to address the specific situation (Lazarus & Folkman, 1984) and was mainly observed in the current study when family members spoke of their support and coping mechanisms employed. Finally, reappraisal occurs when new information is obtained and offers the potential to change earlier appraisals. The primary appraisal in the current

study started with the theme "relief" upon admission to hospital; it is, however, is followed by constant reappraisals resulting in subsequent themes.

Perception of the hospitalization.

As family members initially appraised their situation, they described feeling **relief** when their family member was hospitalized. This represented the first theme under the balancing factor 'Perception of the Hospitalization'. This relief was short lived and soon replaced with **disbelief and shock** as the family members started to appreciate the ramifications and possibility of mental illness as a diagnosis. Rose, Mallinson and Walton-Moss (2002) looked at how families managed the experience of mental illness. They reported several different themes which mirrored the current research study. They reported a sample size of 29 and included three separate interviews over a two year period, which represented a much larger study than the current research. Initially, "families described a sense of crisis and an urgent need to find answers" (Rose, Mallinson & Walton-Moss, 2002, p. 516). This is similar to the experiences which led to hospitalization as described in the current research. Rose, Mallinson and Walton-Moss found "families, on learning of the illness, expressed feelings of unreality and disruption" (p. 516). This is also similar to the described disbelief and shock following admission to hospital and often described as being in a 'fog'.

During the hospitalization, family members described feeling **alone** in their experience and often felt that no one else could relate to their experience, especially as some family members found their own friends and family did not know how to respond or offer support during that difficult time. Feeling alone or isolated were common concepts highlighted in many research articles which explored the experiences or

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                          ┌─────────────────────┐
                          │    Family Member    │
                          └─────────────────────┘
                                     │
                                     ▼
┌──────────────────┐      ┌─────────────────────┐
│ Strange behavior │ ───► │ Functioning prior to│
└──────────────────┘      │ knowledge of illness│
                          └─────────────────────┘
                                     │
                                     ▼
      ┌────────────────────────────────────────────────┐
      │ State of Disequilibrium:  family member feels   │
      │   they can no longer deal with the situation    │
      └────────────────────────────────────────────────┘
                                     │
                                     ▼
      ┌────────────────────────────────────────────────┐
      │ Family member needs to restore equilibrium and  │
      │     decision is made to go to the hospital      │
      └────────────────────────────────────────────────┘
                                     │
                                     ▼
      ┌────────────────────────────────────────────────┐
      │ Balancing Factors Discussed During Interviews:  │
      └────────────────────────────────────────────────┘
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Perception of the First Hospitalization:
Feeling Relief
Feeling Disbelief and Shock
Feeling Alone and Stigma
Feeling the Ripple Effect
Feeling Excluded during Discharge
Changing Expectations and Grief/Loss

PLUS

Situational Supports:
Family and Friends
Support Groups

PLUS

Coping Mechanisms:
Problem focused and Emotion Focused

Realistic perception, adequate situational supports, adequate coping mechanisms.

Distorted perception of the event, no adequate situational supports, no adequate coping mechanisms

New Equilibrium gained: No further crisis

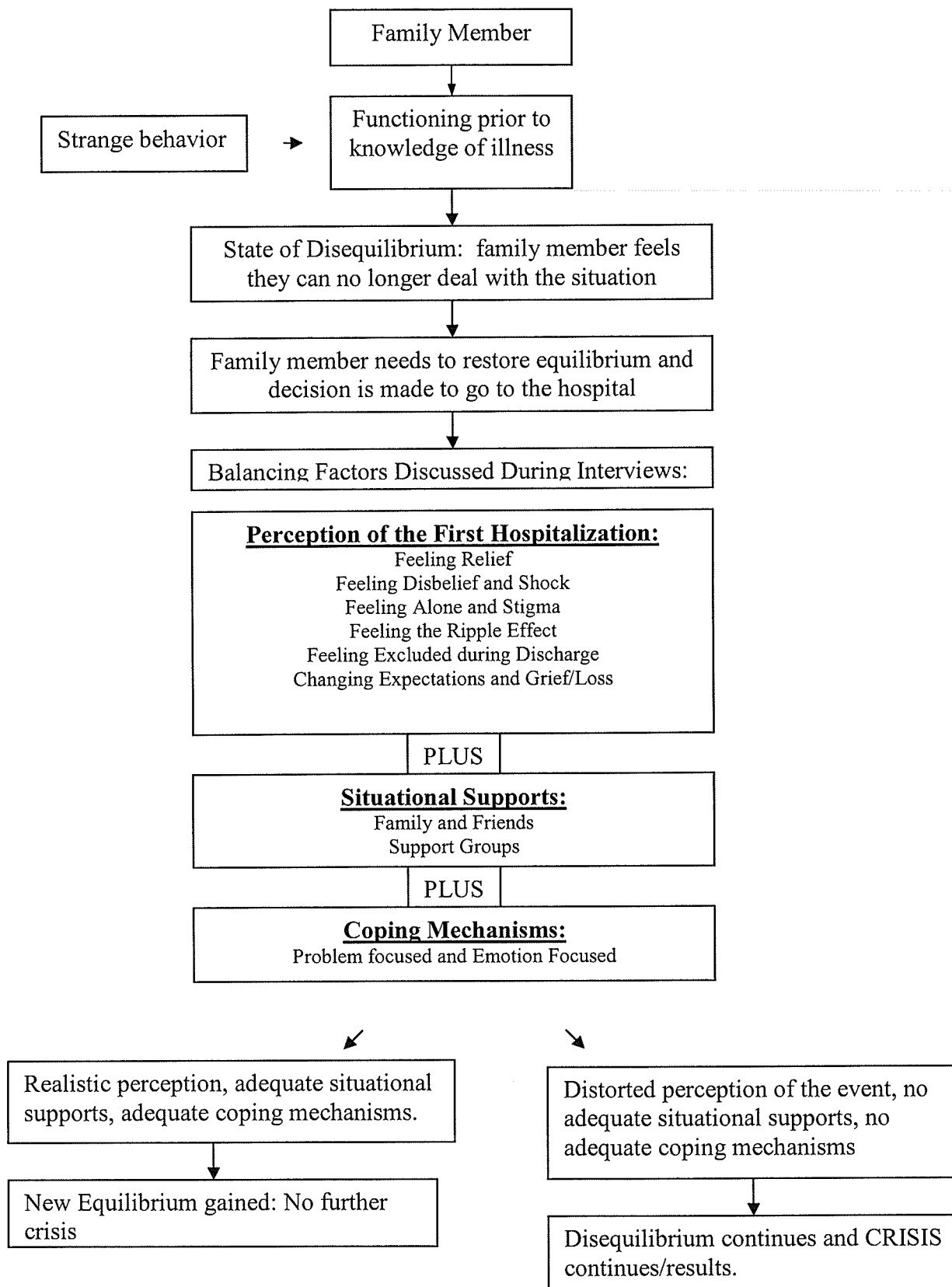Disequilibrium continues and CRISIS continues/results.

Figure 2. Diagrammatic representation of results in current study.

feelings of family members (Ouidette, Gasque-Carter & Curlee, 1999; Mannion &

Meisel, 1996; Milliken & Northcott, 2003; Yamashita, 1998). Yamashita (1998) found

her participants described feeling alone in their experience. In her comparative study of

Canadian and Japanese family members of mentally ill, it was found that "Canadian

counterparts had to endure longer and suffered alone in their caregiving process"

(Yamashita, 1998, p. 519). The major theme in her study of the Canadian participants

was that of struggling alone. The Canadian families also perceived health care

professionals negatively "due to experiences of fragmented care, poor communication

and uncaring or callous manners towards family caregivers" (Yamashita, 1998, p. 519).

Feeling **stigma** was subsumed under feeling alone because stigma greatly

contributed to the theme of feeling alone. Stern, Doolan, Staples, Szmukler and Eisler

(1999) studied family members' narrative stories and found several themes. Two themes

similar to the current findings were "fear of stigmatization and difficulty in finding

external support and confiding in other people" (p. 358). These findings should be

understood and taken into consideration by health care professionals when working with

families in the mental health care setting.

Grief and loss were expressed through the discussion of **changing expectations**.

This was by far the most emotional aspect of the interviews and represented the

devastating loss and grief family members experienced when they appraised their

situation: a situation where their son or daughter had a diagnosis of a mental illness. The

family members realized their dreams for their son's or daughter's future were in

jeopardy. For some family members this meant coming to the realization that their

dreams for their child will never occur and new dreams and expectations will have to be

formed. This was not usually described as something that occurred during hospitalization although the process began at that point. "Families dealt with multiple losses, including loss of pre-illness family relationships" (Rose, Mallinson & Walton-Moss, 2002, p. 516). Karp and Tanarugsachock (2000) also described similar results in their exploration of managed emotions in family caregivers over time. They found that facing the reality of a mental health diagnosis represented a huge emotional time for family members. "Now, caregivers must surrender to the difficult reality that the expectations, aspirations, and hopes that they had for the ill person in their life are unlikely to be realized. Parents, in particular, find it hugely painful to let go of their dreams for their children" (Karp & Tanarugsachock, 2000, p. 16). Their research was broader in scope than the current research study and did not focus on the first admission. The similarity in the research findings adds credibility to the interpretation of the themes as outlined in the results section.

All family members described the **ripple effect** that the hospitalization and the diagnosis had on themselves and on their other family members. Because of the interdependence that exists within a family as a unit, what impacts one person ultimately affects every single person within the family. This impact was typically negative and reflected the shock of the experience of diagnosis as they struggled to make an appraisal regarding how a diagnosis of mental illness was going to impact their own lives and the lives of their ill son or daughter. Hill, Shepherd, and Hardy (1998) specifically examined the impact of caring for someone with a mental illness on the relationships with friends and social life and found that nearly half of those in the study (n=470) reported a negative impact. Teschinsky (2000) examined the impact on parents and siblings living with

someone with schizophrenia. More specific to the hospital experience, Shugar, Smith, and Katz (1992) looked at the needs of families during inpatient transfers between mental health units. They recommended health care professionals respond to families as a whole to "correct their misconceptions, and to respond to their anxieties" (Shugar, Smith, & Katz, 1992, p. 307) therefore suggesting that an impact of the experience on families was anxiety. Researchers have also looked at quality of life (Corring, 2002) and caregiver burden (Doornbos, 2002), but there are no studies which look specifically at the impact of an initial hospitalization on the family. What researchers do agree with is that there is an impact and that the individual with the illness is not the only one who is affected.

Around the time of **discharge,** the family members in this study described being disregarded, despite having been invited to a discharge team meeting. Family members were excluded from providing input or were never informed of the treatment plan, despite having the responsibility and expectation that their son or daughter would be returning to their home, presumably under their care. Ouidette Gasque-Carter and Curlee (1999) found that "most families report that when they ask mental health professionals about their relative's treatment, they either get no response at all or are not included in the treatment. Mental health professionals often discount family members' positive contributions to the treatment process" (p. 523). They concluded that more needs to be done to strengthen the relationship between health care professionals and caregivers. Similarly, parents in Milliken and Northcott's (2003) research described the first hospitalization where they felt marginalized when they "continuously met obstructions whenever they tried to intercede on their child's behalf. At this stage, they described a

miserable existence composed of maintaining vigilance, grieving alone, and grasping at straws" (p. 104).

Situational supports.

'Situational supports' was another balancing factor discussed by the participants. Many offered suggestions for the type of supports they would like to have received. This did not provide themes but did help to identify who and what the family members felt was supportive. Family members identified their own **family or friends** as their main source of support but also mentioned different **support groups** or places where information was readily available. What was interesting was that families were clear that the hospital staff were not perceived as supportive. Ferriter and Huband (2003) found identical results in their study where families recalled that support groups and family were the most helpful while health care professionals were stated as being the least helpful. Mannion and Meisel (1996) compared family members who attended a support group and those who did not. In their conclusions they found "that participation in a support group positively affects key variables in the participant's adaptation to mental illness in a relative... members report more extensive adaptive coping and less subjective burden than do non-members" (para. 30).

Coping mechanisms.

'Coping mechanisms' was the last balancing factor which was explored with the participants. Again, this did not develop into themes; however, the data were categorized into **problem-focused and emotion-focused coping**. Families described a wide range of coping mechanisms they employed during the hospitalization and especially during the time of receiving a diagnosis. This action was representative of secondary appraisal

where family members actively sought out ways of dealing with the current situation. These coping mechanisms involved seeking information or learning about the illness, physically becoming active in aerobics or walking, and going to work where no one knew about their son or daughter so they could feel 'normal' for a short time. The most common coping mechanism was expressing emotion where family members reported crying.

Crying is a type of emotion-focused coping. Therefore, the family members appear to have viewed their crisis or situation as one they had little or no control over. This type of coping was also identified by Nystrom and Svensson (2004) who looked at male caregivers. Family members in their study described crying as a coping mechanism and also described similar feelings previously discussed, including denial, grief, disbelief and shock, feeling alone and loss of control. Knowing how family members cope is only the first step. Family members have also identified a need to learn more coping skills. Hill, Shepherd, and Hardy (1998) found in their survey of carers that they "expressed a wish to learn personal coping strategies and to have their role in helping to manage the illness recognized by professionals" (p. 611).

Some researchers have specifically focused their research on coping. Huong and Slevin (1999) completed a review of the literature with respect to carers. They identified many methods of coping used by caregivers of individuals with schizophrenia. Many of these coping methods were also identified by the participants in the current study. The examples were summarized into three categories, which included psychological coping, physical coping, and social coping. Several examples were provided in each category

which parroted the findings in the current research, including crying, keeping busy, seeking information, using alcohol or smoking, and physical exercise.

A common thread.

Throughout the process of the development of the themes, the theme of feeling 'helpless' was originally identified. Family members described feeling helpless from the point they decided to take their son or daughter to the hospital. At that time family members described being unsure of what was happening and saw themselves as helpless to intervene. Helplessness also surfaced during the hospital stay where families were excluded from information or treatment plans. At the discharge, families described feeling helpless when their son or daughter was often abruptly discharged home with very little support or information provided. The concept of helplessness was seen as a threat which ran through the previously mentioned themes of feeling alone, disbelief and shock, and feeling excluded during discharge.

Helplessness was identified by Nystrom and Svensson (2004) in their study of the perspectives of male caregivers during the time leading up to hospitalization. Similarly, Rose, Mallinson and Walton-Moss (2002) also identified how family caregivers experienced helplessness during the hospitalization, often because they had been excluded. However, there were many more similar studies which, although they did not identify helplessness, did describe feeling alone or isolation (Karp & Tanarugsachock, 2000; Levine & Leginza, 2002; Scharer, 2000; Yamashita, 1998). A related concept to helplessness is hopelessness and the two are intricately linked (Eller, 2000).

What was not found in the results.

A sense of hope was expected but was not found in the current research results. Mallinson & Walton-Moss (2003) identified that the family members in their study described their lives as alternating "between periods of calm and hope and periods of crisis" (p. 516) suggesting family members are either in a state of hope or a crisis. Assuming the common thread of helplessness, and the relationship between helplessness and hopelessness, it makes sense that hope was not found. As discussed by Miller (2000), in situations where coping mechanisms are not adequate, hopelessness and helplessness are present. Yet coping is considered a critical element of hope. This interaction forms a triad. If a sense of hope exists, individuals are less likely to report feeling helpless and are more likely to be engaged in problem-focused coping mechanisms. Engaging in problem-focused coping is also likely to make a person feel less helpless. However, if a sense of hopelessness exists, individuals are more likely to report feeling helpless and are likely to engage in more emotion-focused coping. Lazarus and Folkman (1984) found "an encounter judged as requiring acceptance was associated with a greater emphasis on emotion-focused coping, whereas an encounter the person felt could be acted on was associated with a greater emphasis on problem-focused coping" (p.44). This is further reinforced by the predominance of crying as a coping mechanism in the current study.

In consultation with an 'expert' and family member who runs a local support group, the concept of hope was identified as very important for coping with the situation. It is speculated that family members did not identify feeling hopeful during that initial hospitalization because of the focus of the interview was just the first hospitalization. Her

speculation was that that hope develops later on in the process. In fact, at least two family members confirmed that they did not feel any hope immediately following admission. Hope may not have been described because of the acuity and seriousness of the first hospitalization and the family member's perception that they were helpless in their situation. Karp and Tanarugsachock (2000), in their extensive exploration of the experience of caregivers and their emotions, identified hopelessness as prevalent – especially at the point when family members received a definitive diagnosis. Family members were engaged in shock and disbelief and therefore may have been unable to feel hopeful about the outcome of their circumstances at that time.

<center>*Recommendations for Practice*</center>

Through retrospective discussions of their experiences, family members offered recommendations for changes which would have addressed their needs during the first hospitalization. The recommendations developed were intended for mental health care professionals and were developed from the identified needs of the family.

Recognize the Family

Recognize the family, their experience, their expertise, their contribution, their emotions, and simply their existence. As was evident in the results of the interviews, family members needed recognition from health care professionals. They needed recognition and validation that what they were experiencing was difficult and devastating. At the same time, they needed to be assured that other families have survived the experience of hospitalization and a diagnosis of a mental illness, and they will too. The recognition may be difficult if health care providers view the hospitalization as routine. Admissions and discharges may be routine in nursing care, but

are not everyday occurrences for families who have never had their son or daughter hospitalized, especially for a mental illness. Scharer (2000), in one of the few studies which included the perspective of both the nurses and family members on a child and adolescent mental health unit, found nurses described and treated admissions as routine. Family members may react negatively to the 'routine' attitude of the health care professional as it may undermine and invalidate the family's perception of the experience. Families may describe health care professionals as "uncaring or callous" (Yamashita, 1998, p. 519). Similarly, Nystrom and Svensson (2004) described how health care providers made a difficult situation even worse during hospitalization when "at the first psychiatric consultation [health care providers] appeared to be totally unaware of the trauma the fathers experienced prior to and during their children's first hospitalization" (p. 369). Neglecting this important aspect of the experience early on during the first hospitalization and contact can have devastating effects on the future development of a working relationship.

The first step in recognizing the situation in which families present, is for health care professionals to understand the experiences families have had and the stages they tend to proceed through as described in the current results section. Health care professionals need to keep these experiences and stages in mind when working with a family new to the mental health care system. They need to know that initially most families are in crisis, even though they may describe a sense of relief upon admission. However, shortly thereafter the family may enter a state of disbelief and shock as they start to realize the seriousness of the situation. They may react by asking a lot of questions. They may express the sentiment that the current setting does not seem

appropriate for their son or daughter and feel overwhelmed by the sight of a variety of older mental health clients, as did the participants in the current study.

Within their hospital experience, families all described feeling alone and some may have misinterpreted health care professionals' mannerisms. Families need health care professionals to say 'hello' and ask 'how are you'? These small gestures of recognition are very meaningful for the family during their experience of visiting the hospital and will assist in forming a positive relationship.

Make a Connection

In the current study, many participants described not having developed a relationship with the health care professionals and desperately wanted them to even acknowledge them when they arrived on the hospital unit to visit their son or daughter. This greatly contributed to feelings of being alone and negatively impacted their experience and view of mental health care professionals. Families ultimately reported that hospital staff were not supportive and did not aid in their ability to cope with the situation.

The identified need for a connection with health care professionals in the current study mirrors the findings identified in Cradock, Young and Forquer's (2002) study where "increased receptiveness to family input... [and] ...regular communication with case managers" (p. 259) was needed. Interacting with the family does not mean breaking confidentiality but is an important aspect of ensuring continuity with the client after discharge. Family members are a wealth of information for the health care providers and at the same time need to be kept informed as they are often the main caregivers upon discharge.

Health care professionals need to make themselves available to the family as they would to the client, but recognize that the family members have a different perspective. Making a connection with the family would greatly influence these misconceptions (feeling alone and isolated) and strengthen the relationship between family and health care providers. One way this could be addressed is through the implementation of specific staff designated for access by the family, who would also serve as an advocate and facilitate communication between the family and other health care professionals (Levine & Leginza, 2002). Family members in the current study often stated they felt a designated person should be available to them.

Offer Coping Mechanisms

Family members used a variety of coping mechanisms, which worked to varying degrees. It is important to understand the function of coping in this difficult situation. Miller (2000) discussed the function of coping. She cited Lazarus and Folkman's (1984) conceptualization of coping functions being either emotion-focused or problem-focused. Emotion-focused methods are used when there is the perception that nothing can be done to change or control the situation. Problem-focused coping occurs when it is appraised that the situation can be changed and problem solving techniques are used to cope with the situation. The main coping mechanism used was crying and is considered an emotion-focused method. The predominance of the use of emotion-focused coping, in the current study, also lends support to the semblance of hopelessness.

Recognizing this and informing the family regarding what they can expect to experience during this difficult time will aid in coping with the situation, offers support to the family, and recognizes the reality of the situation. Health care professionals need to

recognize the use of a variety of coping mechanisms and the function coping can have on the family members. Offering practical suggestions for family members during difficult times is supportive, continues to foster a relationship, and validates the feelings and experiences of family members. By addressing coping skills for family members, health care professionals are also sending the message that they care about the family. Coping skills may be as simple as suggesting regular breaks, relaxation techniques, exercise classes, or phoning a friend to vent. Health care professionals may suggest avoiding some coping methods with little overall benefit, such as increasing alcohol consumption or drugs. At the very least, health care professionals should ask family members what they have done in the past to cope with stressful situations. This can prompt families during this difficult time to use coping mechanisms which were successful in the past.

Connect Family Members to a Support Group

One of the greatest situational supports identified by the family members interviewed, is a support group. The need for support, education, and pooling of resources can be addressed through access to a support group. Access to a support group is essential but the 'right' support group can make an even bigger difference. A support group with individuals who are also new may be more useful for family members than a support group of individuals who have been exposed to the mental health care system for many years. The experiences of new family members will be more similar than those who have spent 10 years or more as caregivers. The issues and needs of family members are different than those who have had time to adjust and cope over many years. Furthermore, the developmental issues of having a 20 year old 'child' is different that the needs and issues of a 40 year old 'child' with a mental illness. The Winefield, Barlow,

and Harvey (1998) study supports this conclusion. They studied families' participation and feedback in several support groups and developed recommendations for health care professionals who may be contemplating running a support group. Caregivers "with less than 5 years experience wanted more information about the illness and medications compared with longer term carers, but were less interested in lobbying to improve services and carer-professional communication" (p. 109). Family members not only identified needing access or information about support groups but support groups also provided many benefits. Clearly family members and researchers are all in agreement that support groups are beneficial, desired and aid in support and coping. Health care professionals need to consider this and make a concerted effort to suggest and link with available support groups.

Seeing and hearing other family members talk about their experiences and the potential pooling of resources is invaluable and something most health care professionals are unable to offer directly. By connecting with other family members through a support group, the feelings of isolation and being alone can be further addressed. All family members in the current study described feeling stigma during their experience, often resulting in feeling uncomfortable sharing the experience with others. Family members need to know that they are not isolated in their experience and there are other people out there who have gone through the same situation and survived. A support group can provide external support without the fear of stigmatization.

Provide a Variety of Educational Resources

Access to educational resources is an invaluable support and aids family members in coping with the hospitalization. A 'problem-focused' approach should be encouraged

in providing educational resources as this may increase family members' perception of control, encourage hope, and decrease feelings of helplessness. Providing information which focuses on the abilities of the family member at the time, and tasks that are achievable in dealing with their situation, is essential in a problem-focused approach. This can be as simple as providing a phone number for the psychiatrist and assisting the family member to develop a list of questions to address their concerns. Family members also identified the need for more education during the hospitalization period. It should be noted that many hospital settings do in fact provide written information specific to the family members of first admissions. The handouts vary from one institution to the next and are site specific. None of the family members identified these handouts as being helpful and some of the family members described not being able to comprehend the information at the time of admission. Since the completion of this study, some sites have already implemented new or revised handouts specifically for the family members. The availability of these handouts and the extent of use are not closely monitored or known at this time (L. Newton, personal communication, Dec 16, 2004). Variety is needed and sometimes repetition of educational resources may not be well received and is dependent on the individual's ability to process the information. Some family members may need the information given to them verbally while others may need it in writing. Some family members may need the information immediately or while others may not be able or ready to understand the information for some time. Milliken and Northcott (2003) agreed and recommended "respect, compassion, and education for family members, including practical advice about how to interact and communicate with a psychotic person, should be included in the treatment plan, not left to the family members to obtain on an ad hoc

basis" (p. 110). This requires further assessment of readiness by the health care providers.

There are several studies which examine family education in mental health. Ouidette Gasque-Carter and Curlee (1999) looked at the needs of the family during hospitalization to a long term care facility and also found the second greatest need identified by family members was the need for education about medication and treatment. Jubb and Shanley (2002) also found, in their survey of families where they evaluated services on an inpatient unit, that a lack of information provided to families continues to be neglected area. Education is broadly requested and family members in the current study often described not being able to get the information fast enough, others complained about the medium while other were unable to retain the information due to the fog they described. Therefore an assessment of each individual family's needs is crucial.

Instill Hope

Instilling hope is necessary to combat helplessness and hopelessness and to promoting individual coping with the situation. It is largely dependent on other individuals to facilitate feelings of hope and as long as people describe themselves as alone, there is little chance of them developing hope on their own. Miller (2000) said it best when she explained that "when significant others believe in the possibility of a positive outcome and convey a willingness to share the crisis, hope is enlivened" (p. 524). This is where health care professionals can make a difference. In the current study hope was not identified by the participants. Hope is also inversely linked with helplessness. Family members did describe feeling helpless in the experience and these

descriptions were seen as a thread running through the themes of feeling alone, disbelief and shock, and feeling excluded during discharge. One way of addressing helplessness is to address hope. When phone calls were made to family members to confirm the analysis of the data, hope was identified by family members as essential.

Hope can be instilled in a variety of different methods and is largely dependent on health care professionals' abilities to assess for hopelessness, available coping methods, and implement appropriate interventions that are suitable to the client. Basic interventions, such as explaining to family members that the treatment team needs to spend time with their son or daughter for observation purposes, and that sometimes a diagnosis or treatment plan may not be readily available, are essential. These simple explanations may give family members the understanding that relinquishing control is temporary and, at this point, in the best interest of their child. Reassuring family members that they will be kept informed (only if that is true) when information is available can also assist in instilling hope that something is happening and that the situation is being addressed.

Hope is dependent on the connections of others and the relationships in an individual's life (Miller, 2000). Assisting family members to identify and seek out supportive relationships will aid in instilling hope and addressing feelings of being alone. These supportive relationships could be with health care professionals, support group members, or their own spouse. One of the family members in the current study, whose son has managed to go back to university after his initial psychotic break, indicated she still attends the support group because she wants other family members to know there is hope for recovery. Family members need to hear that the worst case scenario and the

chronic cases they may witness on the same hospital unit as their son or daughter is not

necessarily where their loved one will be in the future.

Clarify Expectations

Clarify expectations and address the parameters of the different health care

professional roles. Scharer (2000), in her study on a child and adolescent mental health

unit, found the parents who were there for the first time often based their expectations on

preconceived stereotypes or media examples of the health care professionals.

Accordingly, many of the participants in the current research study described being

unsure of the roles of the varying health care professionals they encountered and, after

discharge, they often stated they were not sure what the hospital staff 'did' for their son

or daughter. Conflict may arise and foster the perception that the hospital staff is not

supportive because expectations have not been explored or clarified. Some of the

conflicts described by the family members surrounding treatment and confidentiality may

have been prevented had the expectations been clarified.

Health care professionals also need to examine their own understanding of their

roles and recognize that they have an obligation to treat the client within the context of

the family. Milliken and Northcott (2003) also agreed with this focus and suggested

"professional caregivers must recognize the contribution that families make to the

patient's therapy but also accept professional responsibility to provide care for family

caregivers" (p. 110). Further to that, Kaas, Lee, and Peitzman (2003) identified common

barriers for mental health care providers' involvement with family of the mentally ill.

They found "mental health professionals do not often collaborate with family when

providing treatment to the mentally ill, even though research shows better patient

outcomes with family involvement" (p. 741). There are significant barriers on the part of health care professionals identified in the research.

Mental health care professionals need to stop and reflect on their practice. What are their beliefs about the interactions with family members? This is an area in need of further study and beyond the scope of the current study. It is recognized by the researcher that this perspective is an important missing piece in fully understanding the situation and in making more accurate recommendations. Kaas, Lee, and Peitzman however were able to explore mental health care professionals' rationale for a lack of involvement with the family. They found "participants reported that a lack of time and their feelings of conflict about treating the client versus treating the family were the barriers that prevented them most from collaborating with family" (p. 747). Perhaps family members reported feeling excluded more so by health care providers because it was their first experience. Therefore, the family's level of understanding and available information was viewed as less useful or significant by health care providers.

Health care professionals need to continually be made aware of the benefits to the client when increased collaboration occurs with the family. The continued enforcement of a family centered model needs to be supported by management in institutional settings. Changing attitudes and practice is not a simple task and needs to start at the educational preparation level.

Provide Comprehensive Involvement at Discharge

Family members needed to be heard when they expressed concerns or asked questions about discharge. They needed to know what to do next and what not to do. An invitation to a discharge meeting on the day of discharge was not sufficient time for the

family to adjust to the idea of discharge, or to prepare for the possible care that their family member may require once they are at home. Discharge meetings were intimidating and families did not feel they were heard, nor did they feel their input was of any significance. Milliken and Northcott (2003) described the same experiences in their study and referred to a stage where parents became 'disenfranchised' as they realized the situation they were in was one where their experience and expertise as parents was marginalized.

> "Although parents believe they know their child better than anyone else, psychiatrists and other professionals seldom consulted even listened to them. Yet, paradoxically, the young person was often discharged to the parents' home and care. The majority of these parents discovered that their ability to take responsibility for their child was effectively blocked by the law, by mental health professionals, and often their own children" (p. 104).

This stage is analogous to the discharge process described by the participants in the current study who described feeling excluded and disregarded. Chambers, Ryan, and Connor (2001) recommended "a need for a systematic discharge strategy so that carers do not feel they have to take the initiative to seek professional help" (p. 104). Although their study was not specific to mental health, their conclusions and research findings were surprisingly similar. Chambers, Ryan, and Connor (2001) also recommended that health care professionals be more aware of the experiences of caregivers, provide referrals to support groups, address coping strategies including "problem solving, as well as [institute] treatment aimed at emotional catharsis" (p. 104).

When the family has received a new diagnosis of a mental illness and their son or daughter is expected to return home, the family or family members often enter a new role as caregiver. Provencher (2003) discussed the need for mental health care providers to address this role and "assist family members in their efforts to make sense of their caregiving role... as caregiving may be viewed as an expansion of parental responsibilities, a moral obligation, or a challenge sent by God" (p. 603). This represents a process and one which is unknown to family members at the point of the first hospitalization. They are attempting to adjust to a diagnosis, family crisis, new information, and now a possible change in caregiver role.

A Confounding Reality

None of these recommendations is of any use if health care professionals do not interact with the family. One factor which may stop the health care professional from interacting with the family had been alluded to by family members in the study. Several family members stated that health care professionals would not or could not interact with them because their son or daughter had not consented to have information shared with the family. Family members went so far as to suggest that the staff were hiding behind the Personal Health and Information Act or PHIA. This is the legislation which protects personal health-related information from being shared without consent. In a psychotic or thought-disordered state, clients are routinely asked to sign a consent form so that information can be obtained and shared with the family. If this form is not signed then health care professionals have a legal and ethical obligation to maintain confidentiality. Health care professionals have also been warned of financial and licensure type fines which will be enforced should they break this confidentiality. However, when a client

does not consent to have personal health information shared with the family, this does not prohibit the health care professional from sharing information about the hospital unit, visiting hours, available support groups for family, providing educational resources, asking 'how are you?', exploring coping mechanisms, instilling hope, clarifying expectations, etc. Nor does it prohibit the health care professional from asking for consent from the client on subsequent interactions as their recovery progresses. The rights of the client can be maintained while still tending to the needs of the family members. It is not acceptable for health care professionals to exclude communicating with family on all levels because the client has not consented to have their personal health information shared. This would be a misinterpretation of PHIA.

Recommendations are Not Unique

Overall, the participants in this study and their voiced needs resulting in recommendations are not unique. Their needs are complicated because of the 'newness' of their experience and their heightened needs in terms of education and support. Mostly they need to establish a positive working relationship with mental health care providers to ensure their needs are addressed. A positive working relationship is necessary to ensure that future relationships and alliances with health care professionals are fostered. These relationships are the foundation for a team, a team which includes health care professionals, clients, and family members all working together. Mental health care providers are responsible for their assigned client, which also means they are responsible for working with the family due to the intricate and influential relationship between them. Working with families will not be the same as working with the client due to their different needs and different expectations or focus on specific treatment outcomes.

Cradock, Young, and Forquer (2002) looked at family members' views and outcomes to compare them with clients' views and outcomes of treatment. Family members identified several desired outcomes which included "supportive and understanding clinician, effective medication with few side effects, and an excellent relationship with family" (p. 259).

The barriers to working with families are diverse and how to address increasing health care providers' abilities to work with the family poses some difficulty. However, Jubb and Shanley (2002) completed a preliminary needs assessment to collect evaluative data on an existing in-patient mental health unit to provide direction for changing and increasing the involvement of family. They found a lack of information, emotional support, family involvement, and dissatisfaction with staff attitudes towards the family were issues existing on the mental health unit. Identifying the barriers is the first step but then strategies need to be developed to influence change.

Huong and Slevin (1999) created a list of strategies from the literature, itemizing the essentials of support as identified by family caregivers. They contain several components similar to the recommendations previously stated in this current study, and would no doubt increase the involvement of family members. The list included:

- Advice and guidance on use of medication

- Education in the use of cognitive and behavioural strategies

- Education of the total family regarding the need for family support

- Contact information on external support groups

- Family and individual counseling if required

- Education about schizophrenia to improve family knowledge

- Practical advice and guidance, including financial advice

- Education on use of stress-management techniques such as relaxation therapy

- Advice on stress-releasing physical, social and psychological activities

- Access to adequate respite services

- 24-hour access to professionals in emergencies

- Carer and client involvement in care planning

- Access to multi-disciplinary services via a key worker such as a community mental health nurse

- Access to specialist mental health service treatment and assessment centres when required, followed by rapid discharge back to the community supported by a full mental health care team.

If these recommendations have been widely reported in the literature, why do the experiences of the family members continue to suggest they have not been implemented? The available information is either not understood or unknown to health care professionals in the practice setting, or perhaps the recommendations are too difficult to operationalize in the available settings. However, if health care professionals do not believe a problem exists, then there is little motivation or incentive to address practice issues.

Dissemination of Information

As has previously been expressed, the intent of this research was to positively influence practice. During many of the interviews family members asked what was going to happen to their stories and would their time and effort make a difference or contribute to a study that sits on a shelf and collects dust. The experience of the interviews, and the

time and openness with which the family members discussed their own experiences, has

left a lasting impression and desire on the part of the researcher to ensure that this process

was not just for the sake of completing a study. The implications of the current results

have potential use in educational preparation of undergraduate nurses, various practice

areas in mental health, and the research scene. Dissemination of the research findings

should therefore address each of these.

Educational setting.

Communication of this information to the academic arena and instructors who

teach at the Faculty of Nursing will be undertaken. Nurses and other health care

professionals need to be made explicitly aware of the responsibility they have to family

members prior to entry to practice. If students are taught this information early on,

perhaps when exposed to other less than suitable practices and attitudes of nurses in the

practice setting, the negative influences will be minimized. The findings will be

highlighted to ensure they are included in various parts of the curriculum and particularly

in the fourth year of the nursing program where students experience a clinical practice in

the area of mental health. Other educational settings will be sought for presentation of

the research findings, such as local support groups. The benefits supersede all archaic

reasons why healthcare professionals have excluded family and, although there is a

lengthy history between health care professionals and the family, it is time for change.

Practice.

Changing practice is the most difficult challenge. The researcher plans to meet

with a variety of different individuals with decision-making capabilities with the power

and influence to make needed changes. It is anticipated they will be receptive as they are

the same individuals who were initially consulted prior to starting the research. At that time, they clearly identified family-related research as a priority. These individuals will include mental health educators, directors, and managers of mental health units from all hospitals represented in the study. For change to be effective, the recommendations need to be further filtered and relayed to those in the practice setting. The results and the recommendations will also be presented at a national conference for mental health nurses. Nurses from a variety of areas will therefore have the opportunity to hear the results and recommendations and consider the methods that are currently in use in their own practice settings. Further research is needed to fully understand the perspectives of those in the practice setting and how to affect change.

Policy on which practice is based also needs to be reviewed to ensure there is support for continued exploration of the needs of family members including their perspectives. Current policy within the WRHA Mental Health Program supports inclusion of family members in program planning and evaluation. However, operationalization of this policy is not yet complete. The results of this study should provide further impetus for implementation.

Research.

The current research only addressed the perceptions of the family and based recommendations on the information provided by the family members. To place the current research in context, there is a need to explore the perceived barriers of working with families in mental health from the perspective of health care professionals. A particular focus on the first hospitalization would be useful in creating a clearer picture between the data collected and the findings and recommendations of this study. Knowing

how mental health care professionals perceive the experience of a first hospitalization for a family would aid in developing more appropriate recommendations for intervention.

Limitations

The current sample included nine mothers and one father. Exploration and comparison of the experiences of fathers is needed. Several female family members in the current study suggested the needs and experiences of fathers were different than their own as mothers. The researcher attempted to interview the partners or spouses of the female family members interviewed, but the pursuit was not well received. Difficulty in recruiting male participants is something that has been noted by other researchers in mental health (Nystrom & Svensson, 2004). Despite phone calls and discussion, the fathers were unwilling to be interviewed for the project. However, it was interesting to note the number of striking similarities between the findings in Nystrom and Svensson's work with the experiences of fathers in caregiving roles and the current study. The one father interviewed in the current study did not describe an experience dissimilar to the other participants, who were all mothers. Perhaps their experiences are not that different but the research is currently unavailable to make a clear determination.

The current study had a variety of mental illnesses represented. It is unknown whether the needs of the family members are different if their son or daughter suffers from depression, bipolar affective disorder, or schizophrenia. The criterion for inclusion in the current study accepted any diagnosis providing a first hospital admission to a mental health care facility had occurred within the last four years. This time frame allowed for the diagnosis and initial hospital experience to be relatively recent and fresh in the participants' memories. The time frame of four years was chosen because studies

such as Winefield, Barlow, & Harvey (1998) found that caregivers' needs changed as the time from diagnosis increased. They found a difference occurred at about five years. However, it should be noted that the exploration of the needs of family members in the current study was focused on the needs of the family members *at the time of hospitalization.* Thus, there was a reliance on the memories and abilities of the family members to identify their needs accurately.

Family members' experiences and feelings related to the hospitalization experience varied minimally in the current study despite the time since the first hospitalization. This time ranged from two months to four years. Furthermore, family members were re-contacted a year after the initial interview to verify the data. The study findings were presented in verbal and written formats and family members were asked to verify the accuracy. Not one family member changed their story or challenged the interpretation of the presented data. The experience of the first hospitalization was an emotional and significant time in a family member's life. Family members often compared the event to other significant events in their lives such as child birth and implied that those strong memories were unaltered by time. Levine and Leginza (2002) also noted the significance of the first hospitalization in their research of family caregivers in that they "spent more time talking about this experience, seemed to remember it most vividly, and were most profoundly affected by it" (p. 347). It is appropriate to be cautious of retrospective research. However, considering the nature of the hospital experience and the consistency with the data over time it is less likely that memories or perceptions have changed significantly with time.

The majority of participants were accessed through a support group, which has several implications. They may have been unduly influenced by the discussions in previous support group meetings. However, since the focus of the interviews was based on the personal experiences of the family members, it is less likely that their descriptions of their experiences changed as a result of having attended a support group meeting. Further research involving a more diverse group of participants would shed some clarity as to the influence and bias of those attending a support group. However, accessing a support group for participants also meant a more homogenous group in terms of other characteristics. Typically, members of a support group have higher socio-economic status and higher levels of education, as previously observed by various researchers using support groups (Levine & Leginza, 2003). This was the case in the current study. This can impact the credibility of the study and influence how the research findings are interpreted. It may mean the research findings may be more likely to be applicable to mothers who attend a support group and are from a higher socio-economic status with higher levels of education. The research findings may be less applicable to those in a lower socio-economic group, those who have not accessed a support system, or those living in a rural setting. There would need to be some consideration for the variables in the current study before implementing changes or transferring recommendations to another setting. The nature of the recommendations is such that the conscientious implementation of them to similar situations and settings would not likely be harmful. Further research examining the applicability of the findings to other settings and other populations is clearly warranted.

The interviews focused on the family member and not the family as a unit, therefore conclusions can be drawn only with respect to the family member as a part of a family. The participants were all parents of the hospitalized son or daughter. Although this was not the initial intent of the study, the participants who were accessed included parents only. If health care providers are truly addressing the needs of the family, then the needs of siblings and spouses should also be explored.

In conclusion, goals involving changing practice and attitudes, towards the role of family members during a psychiatric hospitalization, are absolutely essential to the success of addressing family members' needs. Challenging practice and the underlying attitudes will be necessary if families, clients, and health care professionals are to become truly one team with one goal: the health, recovery, and success of the individual with mental illness. More research is urgently needed. However, the implementation of recommendations should not be side-lined until more information can be established. The benefit of implementing even one recommendation far exceeds the implications of continuing to practice in the current routine manner.

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Appendix A

Interview Guide

Semi-Structured Interview Questions:

Perception of the Event:

1. Tell me about your experience the first time your mentally ill relative was hospitalized.

2. What were the greatest difficulties that you encountered the first time you mentally ill relative was hospitalized?

Available Situational Supports:

3. What were some supportive aspects you experienced the first time your mentally ill relative was hospitalized? Which supports were most helpful? Probe: What got you through the event?

4. What kinds of support would you like to have received during the hospitalization?

5. What would you like to tell the staff, given the opportunity, about your experience during the hospitalization?

Coping Mechanisms:

6. What did you do to cope with the experience of the first hospitalization?

7. If you could change your first experience to assist families like yours, what would you include or change?

Probes:

Again, based on your experience with mental health services,

1. Tell me more about your experience
2. So, you are saying_____
3. Do you want to elaborate on that?
4. So, what were our thoughts then?
5. Can you tell me what you mean?
6. Can you tell me more?
7. There are no right or wrong answers; I would just like to get your thinking
8. Other families have mentioned… was this a concern for you or something similar?

Closure:

1. Is there anything we have not discussed that you believe we should?

2. Thank you for your time.

Appendix B

Demographic Information

1. What is your relationship to the hospitalized individual?
Your parent
Your child
Your spouse
Other:_____

2. Does the hospitalized individual live with you?
Yes, all the time
Yes, sometimes
No

3. How long was your family member in hospital?
Less than 7 days
7-14 days
15-28 days
more than 28 days

4. What age category do you fit?: 18-29, 30-39, 40-49, 50-59, over 60

5. What is your current employment status?: currently working full time, part time, unemployed

6. What is your current marital status?: married, separated, divorced, single, common-law

7. Sex: Female/Male

8. What was your highest level of education obtained?:

Appendix C

Invitation Letter

My name is Joanne Winsor. I am a student in the Master's program in Nursing at the University of Manitoba. As partial fulfillment of the program, I am conducting a research study entitled "Exploring the Needs of Family Members during a First Hospital Admission for a Mental Illness".

Very little is known about the family members' perceptions of hospitalization and the unique needs of the family members when a member is admitted in mental health. To provide recommendations to improve mental health services I feel it is important to discuss these issues with families.

I would like to speak to people willing to discuss their own thoughts about the mental health in-patient experience as a family member. You are invited to participate because you have valuable information that may assist in making changes to the health care system and benefit all families involved. If you agree to participate, you can expect to be interviewed one to two times for about an hour to two hours each time. The date and time of the interview(s) will be arranged at your convenience. The interview(s) will be audio taped and will involved one to two hours of your time. You will be asked brief demographic information a the beginning of the interview. You will be asked to sign a consent form. You may be contacted after the research study to verify the conclusions of the researcher. All information collected will be kept strictly confidential.

Your participation is voluntary. Should you decide to participate in this study you are free to withdraw at any time with no explanation required. Your name will never be used. Your confidentiality will be maintained. To be included in this study you must meet the following:

1. minimum age of 18

2. identify yourself as being a caregiver or family member

3. had a family member admitted to a hospital in Winnipeg in the last 4 years for the first time

4. Hospital admission was the Mental Health Program/Psychiatry

If you are interested in participating you are welcome to contact me at my office number 204-474-7318. If you have any further questions regarding this research study please feel free to contact me at the aforementioned number or the Chair of the thesis committee Dr. Diana Clarke at 204-787-7878.

Thank you,

Joanne Winsor

Appendix D
Consent Form for Study Participants

Research Project Title: "Exploring the Needs of Family Members During a First Hospital Admission for a Mental Illness".

Researcher: Joanne Winsor - Master's student in the Faculty of Nursing at the University of Manitoba

This consent form, a copy of which will be left with you for your records and reference. is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here. or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of Study:
The purpose of this research is to explore the needs and experiences of family members who have had a member hospitalized for a mental illness in Winnipeg for the first time in the last four years.
You have been asked to participate because you are:
1. are at least 18 years old
2. identify yourself as being a caregiver or family member
3. had a family member admitted to a hospital in Winnipeg in the last 4 years for the first time and the hospital admission was in the Mental Health Program/Psychiatry

Study Procedures:
You will be interviewed once but potentially twice for approximately one to two hours each time at a location of your choice based on some questions developed by the researcher. Some demographic information such as your age will be collected at the beginning of the interview. The researcher will help you fill out the form. The interview will be audio taped with a small black tape recorder. You may be contacted to verify the preliminary findings of the research by phone. You may decline to complete this process at that time.

If you wish to receive a brief summary of the final findings by mail please check the appropriate box below.

I wish to receive a brief summary
of the findings by mail (please   ☐
provide address at the bottom of
consent form).

I do not want to receive any
information by mail regarding   ☐
this research

Risks:
There are no known risks to you as a participant. In the event you become upset after the interview and feel you need to speak to someone, you will be supplied with a phone number and name of a professional trained to speak to people during times of stress.

Benefits:
By participating in the research, there will be no personal benefits gained. The results of the study will be shared with the Winnipeg Regional Health Authority Mental Health Program to improve programming for clients and their families.

Confidentiality:
The data generated from the researcher will be seen by the researcher, the thesis chair and the thesis committee members. The data will be stored securely in a locked place for a period of 10 years. It will then be shredded and destroyed as confidential waste after this time. Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed.

Voluntary Participation:
Participation is voluntary and you are free to withdraw at anytime during the interview. You may also refrain from answering any questions that you choose not to answer.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

_____   _____
Participant's signature   Date

_____   _____
Researcher's signature   Date

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Date: February 28, 2005
Our ref: WinsorUnivManitobaNM3-05

Ms. Joanne Winsor
                    .ca

Dear Ms. Winsor:

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