

RC
514
AFK
2009

**A STUDY TO ASSESS THE CONTENT VALIDITY OF
THE MODIFIED ENGULFMENT SCALE – FAMILY VERSION**

by

Andria Aiello
BScN, McMaster University, 2000

A thesis

presented to Ryerson University

in partial fulfillment of the
requirements for the degree of
Master of Nursing
in the Program of
Nursing

Toronto, Ontario, Canada, 2009

©Andria Aiello 2009

PROPERTY OF
RYERSON UNIVERSITY LIBRARY

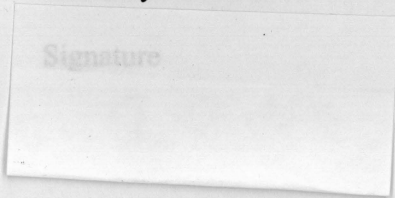
Author's Declaration

I hereby declare that I am the sole author of this thesis.

I authorize Ryerson University to lend this thesis to other institutions or individuals for the purpose of scholarly research.



I further authorize Ryerson University to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.



A Study to Assess the Content Validity of the Modified Engulfment Scale – Family Version

Master of Nursing, 2009

Andria Aiello

Master of Nursing Program

Ryerson University

Abstract

This study was conducted to assess the content validity of the Modified Engulfment Scale – Family Version (MES-FV) which measures the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole. The concept of family engulfment offers a perspective for understanding how a family member's self-concept and a family's identity might incorporate the experience of mental illness. Evidence of content validity was sought by computing a content validity index (CVI), based on ratings of item relevance by seven experts. Case studies, and domain and item matching were also used to obtain evidence pertaining to the content validity of the scale. The study results show strong evidence for the content validity of the MES-FV. The results of the case studies, and domain and item matching were particularly useful in extending the understanding of the relevance ratings (CVIs) which were given for certain MES-FV items.

Acknowledgements

I wish to express my sincere thanks to my supervisor, Dr. Elizabeth McCay, for her expertise, guidance and support throughout the thesis, as well as for helping to make the journey an enjoyable one. I would also like to extend my thanks to my committee members, Dr. Heather Beanlands and Dr. Donna Romano, for their valuable and expert contributions to the thesis.

In addition, I would like to thank Mount Sinai Hospital and the Department of Nursing, as well as my colleagues and fellow team members from 9 South and The Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training for their encouragement and support. I would also like to thank all of the participants who gave generously of their time to complete the evaluation packages.

Special thanks to my parents, Marguerite and Santo, my siblings, Gerry and Mary, my sister-in-law, Frances, and my beautiful niece and goddaughter, Natascia, for their love. I wish to express my appreciation to my fiancé, Peter, for his considerable encouragement and support, and to his family for their sustained interest. I would also like to acknowledge my friends, Donna, Anthony and Anne-Marie, for their encouragement and enthusiasm.

Dedication

I dedicate this thesis to my parents, Marguerite and Santo Aiello, for their love, encouragement and support.

Table of Contents

Chapter I: Introduction.....	1
Background and Significance of the Problem.....	1
Statement of the Problem.....	3
Statement of the Purpose.....	4
Chapter II: Review of Relevant Literature.....	5
Review of Relevant Theoretical Literature.....	5
The Historical Development of the Conceptualization of Engulfment.....	6
The Conceptualization of Family Engulfment.....	9
Self-concept.....	11
Family Identity.....	12
Chronicity and Hope.....	13
Review of Relevant Research.....	14
The Impact of Schizophrenia of Self-concept and Family Identity.....	15
Chronicity and Hope.....	18
Stigma, Social Isolation and Social Roles.....	21
The Skaff and Pearlin Study.....	23
Summary.....	24
Chapter III: Framework.....	26
The Family Engulfment Construct.....	26
The Domains of the Family Engulfment Construct: Conceptual Definitions.....	26
The Domains of the MES-FV: Operational Definitions.....	29
Study Objectives.....	31

Chapter IV: Methods and Procedures.....	32
Research Design.....	32
Sample.....	32
Procedures for Data Collection.....	33
Data Collection Methods.....	34
Data Analysis.....	36
Ethical Considerations.....	38
Chapter V: The Results.....	40
Sample Characteristics.....	40
Case Studies.....	41
Domain and Item Matching.....	42
The Content Validity Index.....	47
Synthesis of the I-CVI, and Domain and Item Matching.....	50
Summary of the Results.....	53
Chapter VI: Discussion.....	55
The Panel of Experts.....	55
The Content Validity Index.....	57
Case Studies.....	60
Domain and Item Matching.....	62
Synthesis of the I-CVI, and Domain and Item Matching.....	65
Chronicity and Recovery in Schizophrenia.....	66
Role Loss in Schizophrenia.....	68
Summary.....	69

Chapter VII: Implications and Conclusion.....	71
Nursing Practice and Education.....	71
Nursing Research.....	73
Theoretical Implications.....	75
Conclusion.....	77
Reference List	90

List of Tables

Table 1 – Characteristics of the Sample.....	41
Table 2 – Case Studies.....	42
Table 3 – The Domains and Their Corresponding Items.....	43
Table 4 – Domain and Item Matching.....	44
Table 5 – I-CVIs.....	49
Table 6 – I-CVIs, and Domain and Item Matching.....	52

Chapter VII. Implications and Conclusion List of Appendices

Appendix A – Letter of Information for a Research Study.....	78
Appendix B – The Family Engulfment Construct and the Domains of the MES-FV.....	80
Appendix C – Case Studies.....	82
Appendix D – Domain and Item Matching.....	85
Appendix E – Relevance Ratings.....	87
Appendix F – General Information.....	89

Chapter I – Introduction

Background and Significance of the Problem

The onset of schizophrenia has a profound impact, not only on an individual's self-concept, but on the self-concepts of his or her family members, and on the identity of his or her family as a whole. Individuals with schizophrenia often experience a changed sense of self through a process of engulfment in which their illness becomes the primary definition of themselves (Lally, 1989). Instead of becoming *part* of the inventory of person, schizophrenia engulfs or pervades the person (Estroff, 1989). Although literature on engulfment among individuals with schizophrenia (Beanlands, McCay & Landeen, 2006; McCay, 1994; McCay, Ryan & Amey, 1996; McCay & Seeman, 1998; McCay et al., 2006; McCay et al., 2007), as well as cancer (Beanlands et al., 2003) and chronic renal disease (Beanlands, 2001; Beanlands et al., 2006), has been growing, studies examining engulfment among families of individuals with chronic illness, specifically schizophrenia, are still limited. The literature suggests, however, that family members also experience a "loss of self" or a loss of identity that comes about as a result of engulfment in the caregiver role (Skaff & Pearlin, 1992). Furthermore, the diagnosis of schizophrenia is often experienced by the family as a destructive force that radically transforms family life (Pejlert, 2001; Tuck, Du Mont, Evans & Shupe, 1997). One of the ways that this transformation of self and family life occurs is through what Estroff called "progressive role restriction," a term which she used to describe what occurs at the level of the individual but which the literature suggests might also be used to describe what occurs at the level of the family as well. As family members focus their time and attention on their ill relative, withdraw from social, leisure and work activities, and lose contact with friends and extended family (Brady & McCain, 2004; Magliano, Fiorillo, De Rosa, Malangone & Maj, 2005; Rudge & Morse, 2004;

Tsang, Tam, Chan & Chang, 2003), they also lose valued social roles as well as the valued conceptions of self derived from those roles. The stigma associated with mental illness also contributes to the social isolation of families and loss of social roles for family members (Brady & McCain; Magliano et al.; Rudge & Morse; Tsang et al.). For some family members, their relative's illness may become so pervasive in activities and thoughts that it may be thought of as completely engulfing the family member. Moreover, all activities of family life may gradually revolve around being a family living with schizophrenia. Thus, "family engulfment" is thought to be an important variable that strongly influences quality of life for families of individuals with schizophrenia. In addition, a scale to measure family engulfment might provide direction for clinical interventions that are geared toward improving quality of life for these families. To date, a scale could not be located in the literature that measures the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole. This study focused on the psychometric evaluation, specifically the content validity, of the Modified Engulfment Scale – Family Version (MES-FV), adapted from the Modified Engulfment Scale (MES) to measure the family engulfment construct in families of individuals diagnosed with schizophrenia.

The term "engulfment" is used by Lally (1989) to refer to "patients' self-concept being increasingly organized around the psychiatric patient role" (p.256). Lally developed a 32-item Engulfment Scale (ES) from a 70-item true-false inventory which he used to elicit information about altered identity, persona, or self-concept, including the degree of alteration around these areas, for 60 psychiatric patients residing in a psychiatric hospital. Higher scores on the ES are interpreted as representing greater engulfment in the patient role. The ES was then modified by McCay (1994), and McCay and Seeman (1998) for use with an outpatient schizophrenia

population and was renamed the Modified Engulfment Scale (MES). The content of the 30-item MES includes a number of domains: (1) an individual's sense of having changed, (2) seeing this change as relatively permanent, (3) the acceptance of a mentally ill label, (4) a loss of normal roles, and (5) negatively comparing oneself to others (Lally; McCay).

A family version of the MES, the MES-FV, was adapted from the MES for use with families to measure the degree to which family members define themselves and their family by their relative's illness – schizophrenia (McCay, Ryan, Patterson & Butterill, 1996). The content of the 30-item MES-FV includes five domains: (1) a family member's sense that they and their family have changed, (2) seeing this change, as well as their relative's illness, as relatively permanent, (3) the family member's acceptance of their relative's mentally ill label, (4) a loss of normal roles for family members, and (5) negatively comparing one's family to other families. The extent to which the MES-FV includes all the major elements relevant to the family engulfment construct, however, has not been examined.

The MES-FV is potentially a clinically relevant measure that may provide direction for clinical interventions that are geared toward minimizing family engulfment and maximizing the healthier aspects of family life. The MES-FV may also provide an instrument for monitoring and evaluating the progress of therapeutic programs for families. It is anticipated that an investigation of the content validity of the MES-FV will contribute to the theoretical development of the family engulfment construct and will ultimately provide directions for interventions designed to improve the quality of life for the family members of persons with schizophrenia.

Statement of the Problem

To date, a scale could not be located in the literature that measures the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole.

While the MES-FV has been adapted from the MES for use with families to measure the degree to which family members define themselves and their family by their relative's illness, namely schizophrenia, the psychometric properties of the MES-FV have not been evaluated. Evaluating the content validity of the MES-FV is a critical early step in enhancing the construct validity of the scale (Polit, Beck & Owen, 2007) and in advancing the study of family engulfment.

Statement of the Purpose

The purpose of this study was to contribute to the psychometric evaluation of the MES-FV. This study evaluated the content validity of the MES-FV as a first step toward providing a standardized family engulfment measure that would assess the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole.

Chapter II – Review of Relevant Literature

Since this study focuses on the content validity of the MES-FV, it is important to include both a theoretical and empirical review. The theoretical review that follows will present a comprehensive overview of the engulfment construct, as well as the family engulfment construct. In the absence of research that specifically addresses the theoretical construct of family engulfment, the empirical review includes studies that have explored concepts and phenomena relevant to the family engulfment construct. The author searched the following databases: CINAHL, Medline and PsycInfo, using different combinations of the following keywords: caregiver burden, chronicity, engulfment, family, hope, identity, labeling theory, schizophrenia, self-concept, self-esteem, social isolation, social roles and stigma. It should be noted that search terms pertaining to specific family roles such as “parents” or “siblings” were not used; rather “family” was used in conjunction with the keywords above to capture literature pertaining to the experiences of all family members. Although the author was interested mostly in studies published within the last 10 years, earlier studies that were particularly relevant to the family engulfment construct, as well as the engulfment construct, were included as well.

Review of Relevant Theoretical Literature

Introduction

The theoretical review will begin with a discussion of the historical development of the conceptualization of engulfment, starting with labeling theory and stigma, and ending with “the process of engulfment” described by Lally (1989). The conceptualization of family engulfment will then be discussed. Given that self-concept and family identity are the objects of the engulfing process for family members and, as such, are intrinsically linked to the family engulfment construct, these will be discussed as well. Rolland’s (1987) conceptual framework

which addresses the impact of chronic illness on the family life cycle will be discussed as Rolland comments specifically on the impact of chronic illness on family identity. Additional concepts, specifically “chronicity” and “hope” which are pertinent to the construct of family engulfment were incorporated into the review.

The Historical Development of the Conceptualization of Engulfment

Labeling theory and stigma.

Labeling theory and the related concept, stigma, provide the theoretical underpinning for the engulfment construct. Labeling theory, which attained substantial prevalence during the 1950s and 1960s, asserts that mental illness does not reside completely within the individual but is at least partly a result of social processing (Beiser et al., 1987). According to labeling theorists, societal forces “convert” individuals with mental illness into a stereotypically defined role and identity (Lally, 1989). Furthermore, as indicated by the labeling theory concept of “secondary deviance,” when individuals try to overcome the stigmatizing effect of a label, their attempts often produce further negative consequences (Lemert, 1967; Link, Mirotznik & Cullen, 1991). For example, out of fear of others’ reactions, individuals with schizophrenia will avoid others and stay to themselves (Lally), resulting in them becoming almost completely isolated.

The concept of labeling is similar to that of stigmatization (Beiser et al., 1987). According to Lemert (1951), “...the formal ascription of a deviating characteristic” (p.12) by means of a label begins the process of “formal social stigmatization.” Labeled individuals then become linked to undesirable characteristics that are in line with prevailing cultural beliefs about a condition (Schulze & Angermeyer, 2003). The negative stereotypes ascribed to labeled individuals are thought to provide justification for the distancing and isolating responses imposed by society (Schulze & Angermeyer).

The diagnosis of schizophrenia may begin the process of formal social stigmatization for the family, as well as for the ill family member. In line with the prevailing and stigmatizing view that individuals with mental illness are sick, bad, unpredictable and dangerous (Beiser et al., 1987; Corrigan & Wassel, 2008), family members of individuals with schizophrenia may also be at risk of becoming linked to many of the same undesirable characteristics. The literature suggests that family members are vulnerable to stigmatization by association, as they are often distanced and treated as inferior when people learn about their relative's illness (Tsang et al., 2003). Having a family member with mental illness may lead to the entire family being seen as inferior (Tsang et al.). Older causal models that attempt to explain schizophrenia in terms of pathological parenting further contribute to the rejection and social isolation of family members (Ferriter & Huband, 2003; Tsang et al.). Furthermore, in keeping with the labeling theory concept of "secondary deviance," family members may isolate themselves out of fear of others' negative reactions (Brady & McCain, 2004; Magliano et al., 2005; Rudge & Morse, 2004; Tsang et al.) and, in the extreme, some family members may become almost completely isolated.

The conceptualization of engulfment.

As stated above, labeling theory and stigma provide the theoretical underpinning for the engulfment construct. Schur (1971) derived the term role-engulfment from labeling theory to describe the tendency of the individual with mental illness to become "caught up in" (p.69) a sick role, and to find that it has become central to his or her overall personal identity or self-concept. In other words, Schur describes the tendency for all activities of life to gradually revolve around being a psychiatric patient and for individuals to eventually see themselves primarily in terms of their illness.

Although Schur (1971) does not apply the concept of role-engulfment to families, he does remark on family reactions to mental illness. According to Schur, the open definition of a family member as mentally ill is often preceded by a long period of accommodation, during which the individual's symptomatic behavior is often normalized by the family. Hospitalization occurs only after a gradual process of redefinition, in which behavior is eventually accepted by the family as symptomatic of illness (Schur).

While labeling theorists, such as Schur (1971), suggest that the process of engulfment involves both the individuals being labeled and the labelers, Lally (1989) argues that these theorists have tended to focus their attention on the role of the labelers, namely the institutions and mental health professionals that are responsible for "...the formal ascription of a deviating characteristic" (Lemert, 1951, p.12) by means of a label or diagnosis. According to Lally, patients are seen by labeling theorists as relatively passive participants, and the role of self-labeling tends to be ignored. Lally modified Schur's term of role-engulfment to "engulfment" to stress the subjective element (McCay & Seeman, 1998).

The process of engulfment.

Lally (1989) integrated quantitative and qualitative approaches in examining the process of how patients become engulfed in a mentally ill self-concept. Lally's description of the process of engulfment is very different from the process which labeling theorists have described. According to Lally, patients are not passive recipients of labels. Lally suggests that the process of engulfment is a sequence with important transitional events defining and moving the process forward, and with changing beliefs and definitions being associated with each stage.

According to Lally (1989), the process of engulfment can be characterized by a sequence of events, which he has divided into beginning, middle and late stages. What underlies the

beginning stage is the individual's need to maintain a positive self-image as a competent person by attempting to separate the self from the stigma and threat of mental illness and fellow patients (Lally). Hallucinations, as well as rehospitalization and continued difficulties, serve as important transitional events which push the process forward (Lally).

The middle stage of this process is characterized by an acceptance of psychiatric problems and a greater identification with fellow patients. Individuals feel more comfortable and more closely aligned with fellow patients than with others, referred to as the "insider/outsider split". The growing belief in individuals that their condition is permanent is involved in the movement from the middle stage to the late stage. The hearing of one's diagnosis seems to serve as an important transitional event which leads to this shift (Lally, 1989).

In the late stage of the process of engulfment, individuals see themselves totally and merely in terms of their illness, and this transformation of self-concept is seen as relatively permanent. An important characteristic of this stage is the mourning of a lost self that was either hoped for or previously experienced (Lally, 1989).

The Conceptualization of Family Engulfment

The existing theoretical and empirical literature suggests that family engulfment may evolve in a similar manner to individual engulfment. Although this process has not been described in stages, similar themes such as initial efforts to protect the ill relative from stigma, gradual acceptance of the illness and its' treatment, greater identification with other families living with mental illness, as well as loss of self and social roles are evident.

The literature suggests that, initially, family members may attempt to separate the ill relative and the family from the stigma and threat of mental illness by either delaying help-seeking (Czuchta & McCay, 2001) or denying the illness (Koukia & Madianos, 2005; Rudge &

Morse, 2004). This perspective is in keeping with Schur's (1971) observation that families are reluctant to identify symptoms of mental illness in a family member. For family members, opinions about how long they think their relative needs to take medication may be thought of as reflecting their conflict around the relative permanence of their relative's condition. Furthermore, family members may experience ambivalence about medication (Rudge & Morse). Medication often enters the lives of family members as an unwelcomed confirmation of their relative's mental illness (Rudge & Morse). As the illness progresses, however, family members often shift from viewing medication as a last resort to fearing that their relative may stop taking it (Rudge & Morse).

Family members may also come to identify more with other families who have a member with mental illness (Rudge & Morse, 2004). Along with this sense of greater identification, there is a parallel process of alienation from others. The stigma associated with schizophrenia may lead families to avoid close social contacts (Magliano et al., 2005; Tsang et al., 2003). Also, family members may be embarrassed by the symptoms and behaviors of their ill relative and avoid bringing others to the home (Brady & McCain, 2004; Magliano et al.). As family members become progressively socially isolated as a consequence of stigma (Tsang et al.), they experience progressive role constriction and may lose valued social roles.

Eventually, family members may come to define themselves and their family to a great extent by their relative's illness. In addition to grieving for their ill relative's lost potential (Brady & McCain, 2004; Rudge & Morse, 2004), family members also mourn a lost self (Skaff & Pearlin, 1992). The progressive role restriction and loss of valued social roles experienced by family members contribute to this "loss of self" (Skaff & Pearlin). Furthermore, not only may a transformation of self occur for family members through a process of family engulfment, but a

transformation of family identity may occur as well, in which there is a loss of the pre-illness family identity. The literature suggests, for instance, that the onset of the illness transforms family life and that the family history becomes divided into two periods of time: the time before the illness and the time after the onset of the illness (Pejlert, 2001, Tuck et al., 1997). In other words, there is the family that is and then there is the family that was. Hence, both a transformation of self-concept and a transformation of family identity may occur through a process of family engulfment, in which family members may see themselves and their family merely in terms of their relative's illness.

Self-concept

"Self concept is the object of the engulfing process" (McCay & Seeman, 1998, p.42). According to Rosenberg (1979), self-concept refers to "the totality of the individual's thoughts and feelings having reference to himself as an object" (p.7), and self-esteem signifies "a positive or negative orientation toward an object" (p.54). In other words, self-esteem is the evaluatory component of the self-concept (McCay & Seeman). A person with high self-esteem has self-respect, and considers himself or herself a person of worth (Rosenberg). A person with low self-esteem, on the other hand, lacks respect for himself, and considers himself unworthy, inadequate, or otherwise seriously deficient as a person (Rosenberg). Furthermore, the drive for self-esteem is thought to be the engine that drives the individual toward competence in a number of roles (McCay & Seeman).

The literature suggests that shame and isolation are experienced by families of individuals with schizophrenia, and that in some cases the stigma is internalized and damages the self-esteem of family members (Tsang et al., 2003). Furthermore, one of the ways that a transformation of self occurs is through progressive role restriction (Estroff, 1989). For family

members, the loss of valued social roles, and the acceptable identities compiled and derived from those roles results in a loss of self, as well as low self-esteem and depressive symptoms (Skaff & Pearlin, 1992). Hence, the more a family member finds themselves engulfed by the illness experience, the greater the threat to their personal self-concept and self-esteem.

Family Identity

For families of individuals with schizophrenia, the identity of the family as a whole may be thought of as the object of the engulfing process as well. Rolland (1987) provides a conceptual framework for thinking about the impact of chronic illness on the family life cycle. Although Rolland's work is in the arena of physical illness, his conceptual framework is useful in thinking about the impact of schizophrenia on the family. Rolland describes three time phases of illness: crisis, chronic and terminal. During the crisis phase, Rolland suggests that the family needs to: create a meaning for the illness event that preserves a sense of mastery and competency; grieve for the loss of the pre-illness family identity; and move toward acceptance of permanent change, all of which are clearly reflected in the conceptualization of family engulfment.

During the chronic phase, Rolland (1987) suggests that the ability of the family to maintain the semblance of a normal life in the face of chronic illness is a crucial task. This is especially challenging for families of individuals with schizophrenia, who are not only dealing with the "abnormal" presence of a chronic illness but are also dealing with the stigma associated with the disorder. Another key task of the chronic phase is the maintenance of maximal autonomy for all family members in the face of a pull toward mutual dependence and caretaking (Rolland). According to Rolland, development normally has a centrifugal, or liberating, effect, while illness has a centripetal, or drawing in, effect. In other words, development normally

results in family disengagement, while chronic illness exerts a centripetal pull on the family system and serves to refocus a family inwardly. Schizophrenia is typically diagnosed during late adolescence (Tuck et al., 1997), a centrifugal period for the family. This is a time when families undergo expected changes associated with individuation of the adolescent and separation of the adolescent from the family (Tuck et al.). As the illness persists, each family member's autonomy and individuation are at risk (Rolland). Parents and siblings are often unable to deal with their own individual or family developmental needs because the focus is on the relative with schizophrenia and sequelae of the illness (Brady & McCain, 2004). Not only do these families see themselves as being "different" from other families and from the family they were prior to the onset of the illness by virtue of the stigma associated with disorder, but the need for family members to sacrifice their own and the family's development as a system in order to deal with the demands presented by the illness can also result in the loss of the pre-illness family identity.

Chronicity and Hope

Family engulfment is also related to the concepts of chronicity and hope. The term "chronicity" is used by Estroff (1989) to refer to "a transformation of a prior, enduring, known, and valued self into a less known and knowable, relatively recent, devalued, and dysfunctional self" (p.194). While Estroff argues that this process "...occurs among and in the eyes of others, and internally, within the person" (p.194), she focuses on the impact of schizophrenia on the individual and the transformation of self that occurs over the course of the illness. Rolland (1987), on the other hand, addresses the impact of "chronic" illness on the family and the changes that occur within the family at different time phases of the illness, namely crisis, "chronic" and terminal. According to Rolland's conceptual framework, one might expect the degree of family engulfment to be minimized during the chronic phase. Rolland suggests, for

instance, that the transition from the crisis to the chronic phase of the illness life cycle offers a “window of opportunity” (p.220) for the family to correct its developmental course. As family members come to see their relative’s illness as relatively permanent, however, one might actually expect the degree of family engulfment to increase. The literature suggests that, for individuals with schizophrenia, labeling the illness or receiving a diagnosis like schizophrenia leads to a fear of permanence and a profound loss of hope for the future (McCay et al., 1996). This fear of permanence and this loss of hope may also be experienced by family members. Family members may struggle with accepting that their ill relative might require medication indefinitely (Rudge & Morse, 2004), that rehospitalization and continued difficulties are possible, and that unemployment and financial dependency might be expected (Tsang et al., 2003). This is a perception of the illness which brings into question expectations for the future. Furthermore, the level of demand and uncertainty associated with a relapsing illness, like schizophrenia, may keep the illness in the forefront of a family’s consciousness, constantly impinging upon their attempts to mitigate engulfment. Not only is there continual grieving for their ill relative’s lost potential (Brady & McCain, 2004; Rudge & Morse), but for these families, their sense of what they were, what they are, and what they are going to be may be changed.

Review of Relevant Research

Introduction

Research that specifically addresses the construct of family engulfment is minimal. Hence, the empirical review that follows will include studies that have explored concepts and phenomenon relevant to the family engulfment construct. As several studies have each explored a number of different concepts relevant to the construct of family engulfment, some studies will be referred to across several different concepts. In keeping with the theoretical review, the

empirical review will begin with a discussion of those studies that have explored the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole. Furthermore, in keeping with the theoretical review, studies that have explored chronicity and hope, as well as stigma, social isolation and social roles, will also be reviewed. For the sake of completion, a review of the literature on engulfment beyond the literature on schizophrenia was undertaken to identify studies relevant to the construct of family engulfment. Skaff and Pearlin's study (1992) is the only study that could be located that was relevant to the family engulfment construct and this study will be discussed separately.

The Impact of Schizophrenia on Self-concept and Family Identity

Tuck et al. (1997) explored the experience of caring for an adult child with schizophrenia using phenomenological methodology. The authors interviewed nine parents who were the primary caregivers of an adult child with schizophrenia. For these participants, the world of the family was transformed by the diagnosis, and time was sharply divided into before and after the diagnosis. While adolescence is a time when families undergo expected changes associated with individuation of the adolescent and separation of the adolescent from the family, active parenting became unending for these participants. Participants described how watching, protecting, seeking help, along with the sacrifice of personal needs became daily activities that consumed resources and challenged their self-identities. Participants struggled to remain lovingly connected to their child while seeking to separate and preserve the self. The diagnosis of schizophrenia, therefore, was experienced by these participants as a destructive force that interrupted and transformed the family life trajectory, and there was a deep and abiding sadness associated with this transformation of family life. Caring for an adult child with schizophrenia altered the participant's life trajectory as well. The participant's goals, values and plans were affected by the

disease. Furthermore, having a child with schizophrenia was a threat to the participant's self-evaluation as a good and successful parent (Tuck et al.).

Similarly, Pejler (2001) sought to illuminate the meaning of parental caregiving with reference to having an adult son or daughter with schizophrenia living in a care setting. Eight parents, three couples, one father and one mother, participated in this qualitative study. The onset of the illness transformed the lives of these families as well. In the narratives, the history of the family was once again divided into two periods of time: the time before the illness and the time after the onset of the illness. Although their son or daughter was living away from home, participants once again spoke about endless parenting, encompassing caregiving responsibilities and worries about their son or daughter. Different ways of dealing with life were disclosed in the narratives. Being involved in one's own interests, likely in an effort to preserve some sense of self, was revealed as being helpful in coping with difficulties. The onset of the illness, therefore, was described as an event that transformed the course of the family. Though they did not serve as primary caregivers, parents continued to provide care for their adult child while reformulating what it meant to be a family and a parent under those conditions (Pejler).

Based on 50 in-depth interviews, Karp and Tanarugsachock (2000) considered how caregivers with a spouse, parent, child or sibling suffering from depression, manic-depression or schizophrenia managed their emotions over time. The authors identified four broad moments in the evolution of the experience of caring for a mentally ill family member. While Tuck et al. (1997) and Pejler (2001) found that endless parenting continued to be a force in the participants' lives, Karp and Tanarugsachock described how participants' eventual recognition that they could not control their family member's illness allowed them to decrease involvement without guilt. Furthermore, participants' eventual recognition that by caring too much they were losing

themselves also allowed them to decrease involvement, thus preserving their identities (Karp & Tanarugsachock). Although not specifically stated, perhaps it was participants' awareness that they were becoming engulfed by the illness experience and their involvement in the caregiver role that enabled them to transition beyond endless parenting.

According to Milliken and Northcott (2003), parents of individuals with schizophrenia are likely to vary their caring practices in response to their adult-child's illness trajectory and the involvement of mental health professionals. Consequently, the authors carried out a grounded theory study to explain the experience of parental caregiving in schizophrenia. In parental caregiving for young adults, the socially prescribed change is toward freedom from management and direction. As parents socialize their children toward independence, they anticipate that their own responsibilities will decrease accordingly. Parents expect to ultimately be emancipated from active parenting. Based upon the qualitative data provided by 29 parent caregivers, Milliken and Northcott found that after a child is diagnosed with schizophrenia, the parents' identity shifts. Initially, participants found themselves disenfranchised from the role they expected to fulfill. Then, they were able to establish a new parental role by finding new ways to exert their rights and responsibilities. Milliken and Northcott have identified four parental identities and the transitions between them: parent of a teen or young adult, becoming marginalized, the disenfranchised parent, embracing the collective, the reenfranchised parent, evaluating my life, and the emancipated parent. Although the authors describe "Redefining Parental Identity" as a linear process, they acknowledge that it seldom, if ever, is, and that the self-identities of these parents respond to the erratic course of the child's mental illness. Similarly, family engulfment may not be a linear process. The degree of engulfment experienced by family members may also

respond to the fluctuating course of the child's schizophrenia illness trajectory (Milliken & Northcott).

Chronicity and Hope

In addition to addressing the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole, the studies by Tuck et al. (1997), Pejler (2001) and Karp and Tanarugsachock (2000) also address chronicity and hope in schizophrenia. According to Tuck et al., the diagnosis of schizophrenia confirmed for participants that something was amiss and completed their search for an answer. At the same time, there was shock and grief associated with the chronic nature of the disease. Participants described living with constantly changing levels of hope. There was a struggle to remain hopeful for a better future for their child, but this hopefulness was tempered by experience and knowledge concerning the fluctuating course of the illness. Participants spoke of hope as a sustaining force that made it possible to seek ways to improve life for their child and themselves. There was also an awareness, however, that hope was inseparable from the risk of disappointment. Thus, hope both sustained participants, and exposed participants to disappointment and renewed grief. Based upon the findings of this study, although not specifically stated, perhaps the degree of family engulfment experienced by family members may be tempered by a sense of hopefulness on one hand, and intensified by the chronic nature of the disease on the other. Furthermore, although not specifically stated, just as the participants in this study described living with constantly changing levels of hope, perhaps family members may live with constantly changing levels of engulfment.

Similarly, in the study by Pejler (2001), participants' narratives revealed sorrow for the "lost child" (p.197). Despite their narrated experiences of their son or daughter as being changed, participants also recognized a core identity, an unchanged and enduring individual, who could

occasionally be glimpsed. This seemed to endorse hope, promising the possibility of a better life for their child. Participants' narratives displayed hope as a sustaining force to seek ways to improve life for their son or daughter, but they also revealed the struggle to remain hopeful (Pejlert).

Contrary to Tuck et al. (1997) and Pejlert (2001) who describe levels of hope as constantly changing, Karp and Tanarugsachock (2000) link hope to particular moments in the evolution of the caregiving experience with a mentally ill family member. For participants, a diagnosis of mental illness provided a medical frame that clarified the situation and provoked a feeling of hope. At a certain point, however, the initial optimism of believing that their loved one's mental illness could be fixed gave way to a sense of its likely permanency. Participants surrendered to the difficult reality that the hopes that they had for their ill relative were unlikely to be realized. Parents, in particular, found it painful to let go of their dreams for their children. Many experienced a profound sadness, a feeling of pervasive grief at having lost a child. Furthermore, their family member's enduring mental illness required that participants not only lower their expectations for their ill relative but also that they lower their own life expectations (Karp & Tanarugsachock).

Lowering expectations was also a strategy used by participants in the study by Rudge and Morse (2004) examining the experience of caring for a relative with schizophrenia after a medication change to atypical neuroleptics. A total of ten caregivers, one spouse, one partner and eight parents, were interviewed in order to reveal their experiences. Expressions of lowered horizons for their sons or daughters were common in the parent caregivers, and were also evident in the two partners of people living with schizophrenia. Participants also spoke of ambivalence about medication. Medication often entered the lives of participants as a confirmation of their

child's or partner's mental illness. As the illness progressed, however, participants went from viewing medication as a last resort to fearing a time when their relative may stop taking it.

Participants' ambivalence about medication seemed to play out, metaphorically, their conflict around the relative permanence of their relative's condition, with this conflict ending in the realization that mental illness may be a permanent condition (Rudge & Morse).

In terms of coping through the lowering of expectations, some of the participants in the study by Rudge and Morse (2004) discussed revising downward their expectations for their ill relative concerning employment. Employment was also identified as a challenge by participants in the study by Tsang et al. (2003). The authors interviewed ten family members of individuals with mental illness, the majority having schizophrenia, to explore sources of burdens on families of individuals with mental illness. Data analyses showed that much of the burden was related to the stigma of mental illness, and inadequate mental health and rehabilitation services, resulting in difficulties experienced by the mentally ill individuals when trying to obtain competitive employment as well as financial difficulties (Tsang et al.).

The degree to which family member perceive illness permanency is reflected in whether or not they are able to remain hopeful for a better future for their relative with mental illness; whether or not they expect their relative to be well in the future; whether or not they believe their relative can look forward to usual life markers, such as marriage; whether or not they believe their relative will always have to take psychiatric medications; and whether they believe their relative will be able to find work in the future or fear that their family might have to provide financial support to their relative indefinitely. Furthermore, whether family members see their relative's illness as relatively permanent is thought to influence family engulfment.

Stigma, Social Isolation and Social Roles

In keeping with the theoretical review, stigma, social isolation and social roles are also pertinent to the construct of family engulfment, and several studies have explored these concepts. As stated, Tsang et al. (2003) interviewed ten family members of individuals with mental illness, the majority having schizophrenia, to explore sources of burdens on families of individuals with mental illness. Much of the burden experienced by participants was related to stigma and thus social isolation. Two types of stigma were identified by participants: 1) stigma by association whereby some of these participants had been distanced by friends and relatives and 2) self-stigmatization whereby others had internalized stigma and avoided social activities. In this study, participants felt ashamed and concealed their relative's illness because they perceived strong stigma in the community. The fear of discrimination began from the time participants noticed the first signs of illness in their relative (Tsang et al.).

Isolation, shame and concealment, as they relate to the experiences of families of individuals with schizophrenia, have been frequently reported in the literature. In order to explore stigma and discrimination towards people with schizophrenia and their family members, Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas and Guimon (2007) developed a qualitative study using focus group methodology with groups of clinically stable schizophrenia outpatients and relatives. Family members commented on how people avoided them after learning that their relative had been diagnosed with schizophrenia (Gonzalez-Torres et al.). Family members also commented that, at times, discrimination was directed at themselves (Gonzalez-Torres et al.). They described instances when they felt ashamed of being related to a person with schizophrenia, and that this led them to self-discrimination and concealment of the illness (Gonzalez-Torres et al.). Similarly, aiming to explore stigma from the perspective of relatives of

people with schizophrenia, Angermeyer, Schulze and Dietrich (2003) conducted focus group interviews with 122 members of advocacy groups. Participants once again spoke about social exclusion in the form of lack of interest and curiosity, ridicule and gossip, as well as discriminating comments (Angermeyer et al.). Participants also spoke about social withdrawal and concealment of the illness (Angermeyer et al.). Phelan, Bromet and Link (1998) examined perceptions of and reactions to stigma among 156 parents and spouses of first-admission psychiatric patients with schizophrenia. While most family members did not see themselves as being avoided by others as a result of their relative's hospitalization, half reported concealing the hospitalization to some degree (Phelan et al.).

The stigma and social isolation experienced by family members of individuals with schizophrenia may also result in social role constriction. In the study by Rudge and Morse (2004) discussed above, participants spoke about the tendency to exist more and more within a subculture of mental illness, in which members share a common bond of having been stigmatized and a unique kinship in understanding each other's experiences. In the study by Karp and Tanarugsachock (2000), also discussed above, participants spoke about social role constriction as well. Participants' increasing isolation was a major source of frustration. As their caregiver role extended for months or years beyond their family member's first episode, participants inhabited an increasingly constricted world dominated by the chronicity of schizophrenia, the often unreasonable demands placed on them, and the feeling that few people understood their turmoil (Karp & Tanarugsachock). Sometimes, participants responded by reconstructing their social circles (Karp & Tanarugsachock). Participants in this study, however, did not speak about stigma, perhaps because its existence is implied in the context of mental illness and social isolation. A further study by Magliano et al. (2005) explored burden and social

networks in families of individuals with schizophrenia versus long-term physical disorders; each relative was asked to complete the Family Problems Questionnaire and the Social Network Questionnaire. Social network was found to be significantly weaker in the schizophrenia group. Furthermore, there was a clear relationship between a reduction in the relatives' social network and increased levels of burden in the schizophrenia group only. According to Magliano et al., these results may be partly related to the stigma still associated with the diagnosis of schizophrenia.

The Skaff and Pearlin Study

Skaff and Pearlin (1992) examined "loss of self", defined as "a loss of identity that comes about as a result of engulfment in the caregiver role" (p.656), in a sample of spouses and adult children caring for a relative with Alzheimer's disease. Although the study did not use engulfment as a conceptual base, the use of the term "engulfment" in the definition of loss of self seems to imply that caregivers see themselves totally and merely in terms of their caregiver role. Loss of self is linked to the family engulfment construct. The construct of family engulfment, however, is multi-dimensional.

Self-loss was measured in Skaff and Pearlin's study (1992) by two items drawn from a larger set of questions asking the caregivers to evaluate "important things in life" they might have lost as a result of their relative's illness. The two self-loss items were: how much have you lost a) a sense of who you are and b) an important part of yourself. Self-esteem was also measured using nine of the 10 items on the Rosenberg Self-esteem Scale and depression was measured using a 7-item subscale of the Hopkins Checklist. The authors also included information regarding the contact that the caregivers had with friends and family members, and the availability of other roles outside that of caregiver. Greater loss of self was found to be

related to limited social contact and lack of social roles outside that of caregiver. It was negatively associated with self-esteem and positively associated with depression. These findings support the interplay between 'loss of self' and progressive role constriction, negative self-esteem, and poor emotional wellbeing, which is similar to what is proposed in relation to family engulfment.

While Skaff and Pearlin (1992) conceptualize "loss of self" as a consequence of caregiving, the process of family engulfment is more complex. Family engulfment is not a consequence of caregiving alone but occurs in the context of the family's response to the entire illness experience. Furthermore, family engulfment is not only concerned with the loss of self experienced by family members but is concerned with the loss of the pre-illness family identity as well. Still, although loss of self was examined in the context of Alzheimer's disease, the study highlights the relevance of the concepts of "social roles" and "self-esteem" to loss of self and to the conceptualization of family engulfment.

Summary

The impact of a schizophrenic illness reaches far beyond an individual's self-concept, extending to their family members' sense of self and the overall family identity. Although "family engulfment" is a term absent from the literature to date, the literature does support the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole. Furthermore, the literature addresses the struggle experienced by family members to remain hopeful for a better future for their ill relative and for themselves, as well as the stigma, social isolation and loss of social roles experienced by family members that are thought to contribute to family engulfment. Overall, the need to advance the study of family engulfment is supported. Moreover, the need for a standardized measure that would assess the degree to which

family members define themselves and their family by their relative's illness, namely schizophrenia, is also supported as such a measure might provide direction for clinical interventions that are geared toward improving quality of life for families of individuals with schizophrenia.

Chapter III – Framework

The Family Engulfment Construct

Family engulfment refers to the degree to which family members define themselves and their family by their relative's illness, namely schizophrenia. In other words, the construct of family engulfment offers a perspective for understanding how a family member's self-concept and how a family's identity may incorporate the experience of mental illness. It is postulated that a transformation of self-concept and family identity occur through a process of family engulfment, in which family members see themselves and their family completely and merely in terms of their relative's illness. This transformation involves a number of dimensions or domains, and these will be discussed below. The discussion of the domains of the family engulfment construct that follows will include a description of both the conceptual and operations definitions of the domains of the construct.

The Domains of the Family Engulfment Construct: Conceptual Definitions

Domain 1: A family member's sense that they and their family have changed.

Both self-concept and family identity are the objects of the engulfing process for family members, and, as such, are intrinsically linked to the family engulfment construct. Integral to family engulfment, therefore, is a family member's sense that they and their family have changed. The illness has a negative impact on the emotional and psychological wellbeing of individual family members (Brady & McCain, 2004; Tsang et al., 2003), which contributes to a family member's sense of having changed. The illness also has a negative impact on the family as a whole (Karp & Tanarugsachock, 2000; Pejler, 2001; Tuck et al., 1997). As the family incorporates the experience of mental illness, there is an erosion of the pre-illness family identity (Pejler, 2001; Tuck et al., 1997). In other words, the family history becomes divided into two

periods of time: the family before the illness and the family after the onset of the illness (Pejlert, 2001; Tuck et al., 1997).

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent.

As family members grieve for the loss of the pre-illness family identity, they may move toward a position of perceiving permanent change (Rolland, 1987). Family members may see not only the loss of the pre-illness family identity as relatively permanent, believing that their family will never be like it was before their relative became ill, but they may also see their relative's illness as relatively permanent. Perceiving illness permanency is the core of the second domain of the family engulfment construct. Opinions about the ongoing need for medication (Rudge & Morse, 2004), hospitalization and financial support reflect the degree to which family members perceive illness permanency. The degree to which family members perceive illness permanency is also reflected in whether or not they are able to remain hopeful for a better future for their ill relative (Karp & Tanarugsachock, 2000; Pejlert, 2001; Tuck et al., 1997). Viewing the illness as "chronic" or permanent is thought to contribute to the engulfment of family members. The engulfment of family members, however, may be counterbalanced by a sense of hope regarding their ill relative's future.

Domain 3: The family member's acceptance of their relative's mentally ill label.

Whether or not family members actually accept their relative's mentally ill label is also thought to be an essential component of family engulfment. Reflecting on family engulfment as a construct that offers a perspective for understanding how a family member's self-concept and how a family's identity may incorporate the experience of mental illness, it stands to reason that the process of family engulfment may require, or at least involve, a recognition and acceptance of the existence of mental illness. Stigma is highly relevant to this domain. Family members may

be reluctant to accept their relative's diagnosis of schizophrenia or even entertain the possibility of such a diagnosis, partly, if not completely, related to the stigma still associated with this diagnosis (Czuchta & McCay, 2001). As family members come to accept their relative's mentally ill label, they may come to define themselves and their family in terms of this label. On the other hand, family members who maintain that their relative is not mentally ill may be less engulfed by the illness experience.

Domain 4: A loss of normal roles for family members.

Stigma is also highly relevant to the fourth domain: a loss of normal roles for family members. Stigma often results in the social isolation of family members (Angermeyer et al., 2003; Gonzalez-Torres et al., 2007; Magliano et al., 2005; Phelan et al., 1998; Tsang et al., 2003). This occurs in two ways: 1) extended family, friends, co-workers and acquaintances may distance themselves from individuals who have a relative with schizophrenia due to the stigma still associated with this diagnosis and 2) family members of individuals with schizophrenia may distance themselves from others in anticipation of stigma, discrimination and rejection (Angermeyer et al., 2003; Gonzalez-Torres et al., 2007; Magliano et al., 2005; Phelan et al., 1998; Tsang et al., 2003). The social isolation of family members may then result in a loss of social roles for family members. Furthermore, family members may begin to feel more comfortable and more closely aligned with other families who have mentally ill relatives than with people who have never known the experience of living with mental illness (Karp & Tanarugsachock, 2000; Rudge & Morse, 2004).

Domain 5: Negatively comparing one's family to other families.

The ability of the family to maintain the semblance of a normal life under the abnormal presence of a chronic illness (Rolland, 1987) is a challenge for families of individuals with

schizophrenia. “Normal”, however, is a relative term. Families of individuals with schizophrenia may not only negatively compare themselves to the family they were before their relative became ill but they may negatively compare themselves to other families as well. Families who have a member with schizophrenia sometimes see themselves as being different from other families because of their relative’s illness and also perceive that others see them as being different (Tsang et al., 2003). The notion of being “different” from other families is reflective of the loss of the “normal” pre-illness family identity (Rolland) as well as the stigma of mental illness.

The Domains of the MES-FV: Operational Definitions

The MES-FV (McCay, Ryan, Patterson & Butterill, 1996) was adapted from the MES (McCay, 1994; McCay & Seeman, 1998) for use with families who have a member with schizophrenia to measure the degree to which family members define themselves and their family by their relative’s illness. A group of clinical experts which included two nurses and two social workers modified the MES in several ways for use with families and renamed it the Modified Engulfment Scale – Family Version (MES – FV). As stated, the content of the 30-item MES-FV includes the five domains discussed above: (1) a family member’s sense that they and their family have changed, (2) seeing this change, as well as their relative’s illness, as relatively permanent, (3) the family member’s acceptance of their relative’s mentally ill label, (4) a loss of normal roles for family members, and (5) negatively comparing one’s family to other families. The domains of the MES-FV, as well as the individual items of the MES-FV that correspond to each domain, are thought to reflect the family engulfment construct.

Domain 1: A family member's sense that they and their family have changed.

There are eight items of the scale corresponding to the first domain – a family member's sense that they and their family have changed – with one item being reversed scored. Three of the eight items are concerned with the negative impact of the illness on the emotional and psychological wellbeing of individual family members. The remaining five items are concerned with the impact of the illness on the family as a whole, including the loss of the pre-illness family identity.

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent.

There are 11 items of the scale corresponding to the second domain – seeing this change, as well as their relative's illness, as relatively permanent – with four items being reversed scored. One of the 11 items is concerned with the perceived permanence of the loss of the pre-illness family identity. The remaining 10 items are concerned with the perceived permanence of the relative's illness. Of these 10 items, six reflect negative opinions about the ongoing need for medication, hospitalization and financial support. The other four items, which are reversed scored, reflect a sense of hope for a better future for the ill relative.

Domain 3: The family member's acceptance of their relative's mentally ill label.

There are four items of the scale corresponding to the third domain – the family member's acceptance of their relative's mentally ill label – with three items being reversed scored. One of the four items reflects the acceptance of mental illness. The remaining three items, which are reversed scored, reflect the denial of mental illness.

Domain 4: A loss of normal roles for family members.

There are only two items of the scale corresponding to the fourth domain – a loss of normal roles for family members. These items are concerned with the social isolation and loss of social roles experienced by family members.

Domain 5: Negatively comparing one's family to other families.

Finally, there are five items of the scale corresponding to the fifth domain – negatively comparing one's family to other families – with one item being reverse scored. These items include statements about those ways in which families who have a member with schizophrenia see themselves as being different from other families because of their relative's illness and also perceive that others see them as being different.

Study Objectives

As previously stated, this study focused on the content validity of the MES-FV and examined the extent to which the MES-FV includes all the major elements relevant to the family engulfment construct. To some extent, the study also examined the fit between the conceptual definitions and operational definitions of the domains of the family engulfment construct described above. The specific objectives of the study included the following: 1) evaluation of each MES-FV item in terms of its relevance to the family engulfment construct; 2) evaluation of the family engulfment construct and the five domains of the MES-FV; and 3) evaluation of the correspondence of the MES-FV items to the MES-FV domains.

Chapter IV – Methods and Procedures

Research Design

This is a methodological study concerned with the content validation of the Modified Engulfment Scale – Family Version (MES-FV). Content validity “examines the extent to which the method of measurement includes all the major elements relevant to the construct being measured” (Burns & Grove, 2009, p.381). Attention was devoted to the items, as well as the domains of the MES-FV. Evidence of content validity was sought by computing a content validity index (CVI), using ratings of item relevance by a panel of experts. Case studies, and domain and item matching were also used to obtain evidence bearing on the content validity of the scale.

Sample

Network sampling.

Participants were identified and recruited through network sampling. Network sampling is a “non-probability sampling method that includes a snowballing technique that takes advantage of social networks...Subjects meeting the sample criteria are asked to assist in locating others with similar characteristics” (Burns & Grove, 2005, p.743). Potential participants were identified by the study investigator, as well as the study investigator’s thesis committee. As a nurse with more than nine years of experience working with individuals with mental illness, including schizophrenia, and their families, the study investigator was well positioned to identify experts in the field with relevant expertise. Furthermore, the study investigator’s thesis committee included three nurses, two of whom also have experience working with individuals with schizophrenia and their family members. Experts who met the inclusion criteria were then asked to assist in identifying other potential experts.

Inclusion and exclusion criteria.

The criteria for inclusion of participants in this study included being a nurse, case manager or social worker with a minimum of five years of experience (cumulative) working with families of individuals with schizophrenia. Potential participants with less than five years of experience were excluded from the study.

Recruitment.

A total of 13 experts were contacted; all of them met the inclusion criteria and all of them indicated that they were interested in receiving information about the study. A total of 13 evaluation packages were sent out; evaluation packages were sent out to nine nurses and four social workers. Seven experts, six nurses and one social worker, completed and returned the evaluation packages, and thus constituted the sample. Lynn (1986), and Polit and Beck (2006) advise a minimum of three experts but indicate that more than 10 is unnecessary. They recommend that with a panel of five or fewer experts, all must agree on the content validity, but when there are six or more judges, the standard can be relaxed.

Procedures for Data Collection

Following approval of the study by the Research Ethics Board at Ryerson University, potential experts were contacted by the investigator and, if they met the inclusion criteria specified above, asked whether or not they were interested in receiving information about the study. If they indicated that they were interested in receiving information about the study, a letter of information (Appendix A) was mailed to them along with an evaluation package.

Each evaluation package included a description of the family engulfment construct and the domains of the MES-FV (Appendix B), along with three data collection tools to be completed. These three data collection tools, namely the case studies (Appendix C), domain and

item matching (Appendix D) and item relevance ratings (Appendix E), were developed to evaluate the content validity of the MES-FV. Participants were also asked to provide some general information about their experience as a nurse or social worker such as their area of practice, years in their specialty and years of experience working with families (Appendix F). Basic demographic information, including age and gender, was also requested. Once completed, participants were asked to mail the evaluation package back to the investigator in the stamped self-addressed envelop provided. They were given one week to complete and return the evaluation package. After one week, they were telephoned by the investigator, and reminded to complete and return the evaluation package.

Data Collection Methods

Case studies.

In order to evaluate the family engulfment construct and the five domains of the MES-FV, the participants were provided with a description of the family engulfment construct, as well as a description of each of the five domains of the MES-FV (Appendix B). They were also provided with two case studies (Appendix C), each illustrating two or more of the five domains of the MES-FV. For each case study, the participants were asked to indicate whether each of the five domains of the MES-FV was present or absent. The first case study was about a family who was experiencing a first episode of schizophrenia while the second case study was about a family who had been living with schizophrenia for ten years. The study investigator wrote these case studies based on the literature exploring the experiences of families living with schizophrenia, as well as her own clinical experience working with individuals with schizophrenia and their family members. Furthermore, the study investigator's supervisor, who has a wealth of clinical and

research experience in the area of schizophrenia, reviewed the case studies to ensure that they reflected the experiences of families who have a member with schizophrenia.

Domain and item matching.

In order to evaluate the correspondence of the MES-FV items to the MES-FV domains, the participants were provided with a list of the five MES-FV domains and the 30 MES-FV items (Appendix D). They were asked to refer back to Appendix B for a description of each of the five MES-FV domains. Beside each MES-FV item, the participants were asked to indicate the corresponding domain.

The content validity index (CVI).

Lastly, the most widely reported measure of content validity among nurse researchers is the content validity index, or CVI (Polit & Beck, 2006; Polit, Beck & Owen, 2007). The CVI refers to the “degree to which an instrument has an appropriate sample of items for the construct being measured” (Polit & Beck, p.493). Researchers compute two types of CVIs: the item-level CVI, or I-CVI, and the scale-level CVI, or S-CVI (Lynn, 1986; Polit & Beck). The I-CVI involves the content validity of individual items and the S-CVI involves the content validity of the overall scale (Lynn; Polit & Beck). In order to determine the I-CVI and the S-CVI for the MES-FV, the participants were provided with a list of the 30 MES-FV items (Appendix E). They were asked refer back to Appendix B for a description of the family engulfment construct and the domains of the MES-FV. The participants were asked to rate each MES-FV item in terms of its relevance to the family engulfment construct using the following scale: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant (Davis, 1992).

Data Analysis

Sample characteristics.

Nominal-scale demographic data including profession, area of practice and gender were reported in terms of frequency and percent. The range, mean and standard deviation were calculated for ratio-level and interval-scale demographic data including years in specialty, years of experience working with families (cumulative) and age.

Case studies.

For each of the two case studies, participants' responses were organized by domain and analyzed in terms of the number of participants who identified each domain as being present and the number of participants who identified each domain as being absent. Participants' responses were also analyzed in terms of the percentage of participants who correctly identified each domain as being either present or absent.

Domain and item matching.

For the domain and item matching, participants' responses were organized in terms of the five domains of the MES-FV and their corresponding items. For each item, participants' responses were analyzed in terms of the number and percentage of participants who identified the item as corresponding to the correct domain. Items which achieved a percent agreement of at least 71%, that is those items which were identified by at least five of the seven participants as corresponding to the correct domain, were judged as being highly relevant to the domain. A percent agreement of at least 71% takes into account the risk of chance disagreements, as well as non-chance disagreements if an expert did not understand the task or had a biased viewpoint.

The content validity index (CVI).

The item-level content validity index, or I-CVI, which refers to the content validity of individual items, was calculated for each item of the MES-FV as the proportion of participants giving the item a relevance rating of 3 (quite relevant) or 4 (highly relevant). For a scale to be judged as having excellent content validity, it would be composed of items with I-CVIs that meet Lynn's (1986) criteria of a minimum I-CVI of 0.78 for six to 10 experts/participants (Polit & Beck, 2006). An MES-FV item that was given a relevance rating of 3 or 4 by five out of seven participants would have an I-CVI of 0.71 and would not meet Lynn's criteria. An MES-FV item that was given a relevance rating of 3 or 4 by six out of seven participants, however, would have an I-CVI of 0.86 and would meet Lynn's criteria. For the MES-FV to be judged as having excellent content validity, therefore, it would be composed of items with I-CVIs of 0.86 or higher for seven experts/participants.

The scale-level content validity index, or S-CVI, which refers to the content validity of the overall scale, was computed using two distinct calculation methods: 1) the S-CVI/UA, or the universal agreement calculation method and 2) the S-CVI/Ave, or the averaging calculation method. The S-CVI/UA was calculated as the proportion of items on the MES-FV that achieved a relevance rating of 3 or 4 by *all* the participants. The S-CVI/Ave was calculated as the average of the I-CVIs for all items on the MES-FV. According to Polit & Beck (2006) and Polit et al. (2007), for the MES-FV to be judged as having excellent content validity, it would have an S-CVI/Ave of .90 or higher.

Synthesis of the I-CVI, and domain and item matching.

Each item of the MES-FV represents one of the five domains of the family engulfment construct. The content validity of individual items, therefore, was examined in relation to the

domains of the scale. Firstly, in order to determine the proportion of items within each of the five domains of the MES-FV that were rated as being relevant to the family engulfment construct, the items were organized in terms of the five domains and, within each domain, the I-CVIs were listed from highest to lowest. The data were analyzed in terms of the percentage of items within each domain that had an I-CVI of 0.86 or higher.

Secondly, in order to obtain more information about the content validity of individual items for the MES-FV, each MES-FV item was analyzed in terms of its I-CVI, as well as in terms of the percentage of participants who identified the item as corresponding to the correct domain. As previously stated, for the MES-FV to be judged as having excellent content validity, it would be composed of items with I-CVIs of 0.86 or higher for seven experts/participants. Furthermore, items which achieved a percent agreement of at least 71%, that is those items which were identified by at least five of the seven participants as corresponding to the correct domain, were judged as being highly relevant to the domain. Evidence of the content validity of individual items was strongest for items with both an I-CVI of 0.86 or higher and a percent agreement of at least 71%.

Ethical Considerations

This study underwent ethics review and gained approval from the Research Ethics Board at Ryerson University. Participation in the evaluation of the MES-FV was entirely voluntary, and completion of the evaluation package and return via self-addressed stamped envelope implied participants' consent to participate in this study. Efforts were made to maintain anonymity and protect confidentiality; participants were instructed not to include any identifying information on any part of the evaluation package, and only the investigator and thesis committee members had

access to participants' responses. Due to the method of recruitment and the small sample size, however, participants were informed that there were limitations related to protecting anonymity.

Sample Characteristics			
Profession			
Nurse	7	100%	
Social Worker	7	100%	
Area of Practice			
Mental Health / Psychiatry	7	100%	
Gender			
Female	7	100%	
Age			
Mean	12.3	SD	7.03
Range	5-25		
Years of experience with the exception of one participant who is a social worker, and all of them were female. The participants in this study were an experienced group of health care professionals with an average of 16 years in mental health psychiatry and an average of more than 12 years of experience working with families.			

Case Studies

For each of the two case studies, the participants were asked to indicate whether each of the five domains of the MES-FV was present or absent. The results are presented in Table 2. In the first case study about a family who is experiencing a first episode of schizophrenia, domains 1, 2 and 3 are present while domains 4 and 5 are absent. In other words, domains 1, 2 and 3 are illustrated in the case study while domains 4 and 5 are not. In the second case study about a family who has been living with schizophrenia for ten years, all of the domains are present.

Overall, there was 100% agreement for three out of the five domains of the MES-FV for case study #1 and 100% agreement for all five domains of the MES-FV for case study #2. Specifically, for case study #1, all of the participants correctly identified domains 1 (change) and 3 (illness acceptance) as being present and domains 4 (negative comparisons) as being absent.

Chapter V – The Results

The results of this study are presented in five sections: 1) sample characteristics, 2) case studies, 3) domain and item matching, 4) content validity index and 5) synthesis of the item-level content validity index, and domain and item matching.

Sample Characteristics

Seven individuals with clinical expertise in mental health/psychiatry who had worked specifically with families of individuals with schizophrenia comprised the sample for this study. Sample characteristics are shown in Table 1. All of the participants practiced in the area of mental health/psychiatry; one participant indicated that her area of practice was primary mental health care. All of them were nurses with the exception of one participant, who was a social worker, and all of them were female. The participants in this study were an experienced group of health care professionals with an average of 16 years in mental health/psychiatry and an average of more than 12 years of experience working with families.

Ethical Considerations

This study underwent ethics review and gained approval from the Research Ethics Board at Ryerson University. Participation in the evaluation of the MES-FV was entirely voluntary, and completion of the evaluation package and return via self-addressed stamped envelope implied participants' consent to participate in the study. Efforts were made to maintain anonymity and protect confidentiality; participants were instructed not to include any identifying information on any part of the evaluation package, and only the investigator and thesis committee members had

Table 1

Characteristics of the Sample (N = 7)

Demographic Variables	Frequency	Percent
Profession		
Nurse	6	86%
Social Worker	1	14%
Area of Practice		
Mental Health / Psychiatry	7	100%
Gender		
Male	0	
Female	7	100%

Demographic Variables	Range	Mean	SD
Years in specialty	5-30	16	8.37
Years of experience working with families (cumulative)	5-25	12.3	7.03
Age	29-63	44.7	11.88

Case Studies

For each of the two case studies, the participants were asked to indicate whether each of the five domains of the MES-FV was present or absent. The results are presented in Table 2. In the first case study about a family who is experiencing a first episode of schizophrenia, domains 1, 2 and 3 are present while domains 4 and 5 are absent. In other words, domains 1, 2 and 3 are illustrated in the case study while domains 4 and 5 are not. In the second case study about a family who has been living with schizophrenia for ten years, all of the domains are present.

Overall, there was 100% agreement for three out of the five domains of the MES-FV for case study #1 and 100% agreement for all five domains of the MES-FV for case study #2. Specifically, for case study #1, all of the participants correctly identified domains 1 (change) and 3 (illness acceptance) as being present and domain 5 (negative comparisons) as being absent.

Only 43% of the participants, however, correctly identified domain 2 (permanence) as being present and only 43% correctly identified domain 4 (role loss) as being absent. For case study #2, all of the participants correctly identified all of the domains as being present.

Table 2

Case Studies

Domain	Whether domain was present or absent	Number of participants who identified domain as present (N = 7)	Number of participants who identified domain as absent (N = 7)	Percent Agreement
Case Study #1: First Episode				
Domain 1: Change	Present	7	0	100%
Domain 2: Permanence	Present	3	4	43%
Domain 3: Illness Acceptance	Present	7	0	100%
Domain 4: Role Loss	Absent	4	3	43%
Domain 5: Negative Comparisons	Absent	0	7	100%
Case Study #2: Long-term				
Domain 1: Change	Present	7	0	100%
Domain 2: Permanence	Present	7	0	100%
Domain 3: Illness Acceptance	Present	7	0	100%
Domain 4: Role Loss	Present	7	0	100%
Domain 5: Negative Comparisons	Present	7	0	100%

Domain and Item Matching

The domains and their corresponding items are listed in Table 3. Furthermore, the results of the domain and item matching are shown in Table 4 and are presented by domain below. Special attention was paid to those items which achieved a percent agreement of at least 71%; that is those items which were identified by at least five of the seven participants (71%) as corresponding to the correct domain. It was also noted when *two or more* participants incorrectly identified an item as corresponding to the *same* domain.

Table 3

The Domains and Their Corresponding Items

Domain 1: A family member's sense that they and their family have changed

- Item #8: For our family to be really well, our family will have to go through a change
- Item #14: I am often depressed because of my relative's illness
- Item #19: I am afraid of losing my mind
- Item #20: I worry that other members of my family may become mentally ill
- Item #21: We are damaged as a family by our relative's illness
- Item #24: There are many things we used to be able to do as a family that we can't do now
- Item #25: Right now, we are no longer the family we were before our relative became ill
- Item #30: We are basically the same family we were before our relative became ill*

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent

- Item #5: Our family will never be like it was before our relative became ill
- Item #6: At some point in time, our relative will not need psychiatric medications*
- Item #9: "Once a mental patient, always a mental patient"
- Item #10: Once having been hospitalized, there is a good chance of it happening again
- Item #11: Our relative will probably need to be hospitalized again
- Item #16: Our relative will always have to take psychiatric medicine
- Item #22: It is good for our relative to stay in hospital for a long time
- Item #23: I fear that my family might have to provide financial support to my relative indefinitely
- Item #26: Our relative can look forward to being married or having a steady partner*
- Item #27: I expect my relative to be well in the future*
- Item #29: Our relative will be able to find work in the very near future*

Domain 3: The family member's acceptance of their relative's mentally ill label

- Item #2: In my opinion, my relative is mentally ill
- Item #4: Our relative is healthy in body and mind*
- Item #15: My relative really does not need psychiatric care at all*
- Item #28: Our relative's mind is normal*

Domain 4: A loss of normal roles for family members

- Item #12: We can only be friends with other families who have mentally ill relatives
- Item #17: My relative's illness keeps me from having close friends

Domain 5: Negatively comparing one's family to other families

- Item #1: Our family manages as well as most families do*
- Item #3: Because of our relative's illness, we can't do the things that other families do
- Item #7: Our friends and family see us only as a family with problems
- Item #13: We are more worried and nervous that other families
- Item #18: We will always be different from other families because of our relative's illness

*Items with an asterisk beside are reversed scored

Table 4

Domain and Item Matching

Domains and corresponding items	Number of participants who identified item as corresponding to domain (N = 7)	Percent agreement
Domain 1: A family member's sense that they and their family have changed		
Item #8	5	71%
Item #14	6	86%
Item #19	6	86%
Item #20	5	71%
Item #21	4	57%
Item #24	5	71%
Item #25	7	100%
Item #30*	5	71%
Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent		
Item #5	4	57%
Item #6*	4	57%
Item #9	7	100%
Item #10	7	100%
Item #11	6	86%
Item #16	6	86%
Item #22	4	57%
Item #23	6	86%
Item #26*	4	57%
Item #27*	3	43%
Item #29*	4	57%
Domain 3: The family member's acceptance of their relative's mentally ill label		
Item #2	6	86%
Item #4*	6	86%
Item #15*	6	86%
Item #28*	7	100%
Domain 4: A loss of normal roles for family members		
Item #12	5	71%
Item #17	7	100%
Domain 5: Negatively comparing one's family to other families		
Item #1*	5	71%
Item #3	5	71%
Item #7	4	57%
Item #13	6	86%
Item #18	7	100%

*Items with an asterisk beside are reversed scored

Domain 1: A family member's sense that they and their family have changed.

There are eight items of the MES-FV which correspond to the first domain of the scale: a family member's sense that they and their family have changed. The percentage of participants who correctly identified each of these eight items as corresponding to the first domain ranged from 57% to 100%. Overall, seven of the eight items (#8, #14, #19, #20, #24, #25 and #30) were identified by at least 71% of the participants as corresponding to domain 1. Specifically, item #25 was identified by 100% of the participants as corresponding to the first domain, while item #21 was identified by only 57% of the participants as corresponding to domain 1. For item #20: "I worry that other members of my family may become mentally ill," both participants who did not choose domain 1 chose domain 3 (illness acceptance) instead. The same was true for item #30: "We are basically the same family we were before our relative became ill," both participants who did not choose domain 1 chose domain 3. For item #24: "There are many things we used to be able to do as a family that we can't do now," both participants who did not choose domain 1 chose domain 4 (role loss) instead.

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent.

Eleven items comprise the second domain of the MES-FV: seeing this change, as well as their relative's illness, as relatively permanent. The percentage of participants who correctly identified each of these 11 items as corresponding to the second domain ranged from 43% to 100%. Overall, five of the 11 items (#9, #10, #11, #16 and #23) were identified by at least 86% of the participants as corresponding to domain 2. These items were concerned with illness permanence in the context of being a "mental patient," hospitalization, medication and financial support. The remaining six items (#5, #6, #22, #26, #27 and #29) were identified by 57% or less of the participants as corresponding to domain 2; four of these six items (#6, #26, #27 and #29)

were reversed scored. For item #5: "Our family will never be like it was before our relative became ill," all three participants who did not choose domain 2 chose domain 1 (change) instead. For item #6: "At some point in time, our relative will not need psychiatric medications," all three participants who did not choose domain 2 chose domain 3 (illness acceptance) instead. The same was true for item #22: "It is good for our relative to stay in hospital of a long time," all three participants who did not choose domain 2 chose domain 3. For item #27: "I expect my relative to be well in the future," all four participants who did not choose domain 2 chose domain 3 instead. Furthermore, for items #6, #11, #16, #22 and #27, all of the participants who did not choose domain 2 chose domain 3 instead. Finally, for items #26 and #29, all of the participants who did not choose domain 2 chose either domain 3 or domain 4 (role loss).

Domain 3: The family member's acceptance of their relative's mentally ill label.

The third domain of the MES-FV, the family member's acceptance of their relative's mentally ill label, is comprised of four items. The percentage of participants who correctly identified each of these four items as corresponding to the third domain ranged from 86% to 100%. Overall, all of the items (#2, #4, #15 and #28) were identified by at least 86% of the participants as corresponding to domain 3. Specifically, item #28 was identified by 100% of the participants as corresponding to the third domain.

Domain 4: A loss of normal roles for family members.

Only two items comprise the fourth domain of the MES-FV: a loss of normal roles for family members. Overall, both of the items were identified by at least 71% of the participants as corresponding to domain 4. Specifically, item #17 was identified by 100% of the participants as corresponding to the fourth domain. For item #12: "We can only be friends with other families

who have mentally ill relatives,” both participants who did not choose domain 4 chose domain 5 (negative comparisons) instead.

Domain 5: Negatively comparing one’s family to other families.

Finally, there are five items of the MES-FV which correspond to the fifth domain of the scale: negatively comparing one’s family to other families. The percentage of participants who correctly identified each of these five items as corresponding to the fifth domain ranged from 57% to 100%. Overall, four of the five items (#1, #3, #13 and #18) were identified by at least 71% of the participants as corresponding to domain 5. Specifically, item #18 was identified by 100% of the participants as corresponding to the fifth domain, while item #7 was identified by only 57% of the participants as corresponding to domain 5. For item #3: “Because of our relative’s illness, we can’t do the things that other families do,” both participants who did not choose domain 5 chose domain 4 (role loss) instead. Finally, for item #7: “Our friends and family see us only as a family with problems,” all three participants who did not choose domain 5 chose domain 4 instead.

The Content Validity Index

Item-level content validity index (I-CVI).

The content validity of individual items, or I-CVI, refers to the proportion of experts/participants giving an item a relevance rating of 3 (quite relevant) or 4 (highly relevant). The I-CVIs for the MES-FV items, listed from highest to lowest, are shown in Table 5. Thirteen items achieved a relevance rating of 3 or 4 by all of the participants and an I-CVI of 1.0; six items achieved a relevance rating of 3 or 4 by six of the seven participants and an I-CVI of 0.86; eight items were given a relevance rating of 3 or 4 by five of the seven participants and an I-CVI of 0.71; and three items were given a relevance rating of 3 or 4 by four of the seven participants

and an I-CVI of 0.57. In total, 19 of the 30 MES-FV items had I-CVIs of 0.86 or higher. Twenty-seven items, however, had I-CVIs of at least 0.71. Of the three items that had I-CVIs of 0.57 (#1, #26 and #27), all of them are reversed scored and two of them (#26 and #27) belong to the second domain (permanence) of the scale.

Scale-level content validity index (S-CVI/UA and S-CVI/Ave).

The content validity of the overall scale was determined using both the scale-level content validity index, universal agreement calculation method (S-CVI/UA) and the scale-level content validity index, averaging calculation method (S-CVI/Ave). The S-CVI/UA refers to the proportion of items on the scale that achieved a relevance rating of 3 or 4 by *all* the participants and an I-CVI of 1.0. Thirteen of the 30 items on the MES-FV achieved a relevance rating of 3 or 4 by *all* the participants and an I-CVI of 1.0, resulting in an S-CVI/UA of 0.43. The S-CVI/Ave is the average of the I-CVIs for all items on the scale. The S-CVI/Ave for the MES-FV was 0.85.

Table 5

I-CVIs

The MES-FV Items	I-CVI ¹
Item #2: In my opinion, my relative is mentally ill	7/7 = 1.00
Item #5: Our family will never be like it was before our relative became ill	7/7 = 1.00
Item #7: Our friends and family see us only as a family with problems	7/7 = 1.00
Item #11: Our relative will probably need to be hospitalized again	7/7 = 1.00
Item #12: We can only be friends with other families who have mentally ill relatives	7/7 = 1.00
Item #13: We are more worried and nervous that other families	7/7 = 1.00
Item #14: I am often depressed because of my relative's illness	7/7 = 1.00
Item #17: My relative's illness keeps me from having close friends	7/7 = 1.00
Item #18: We will always be different from other families	7/7 = 1.00
Item #20: I worry that other members of my family may become mentally ill	7/7 = 1.00
Item #21: We are damaged as a family by our relative's illness	7/7 = 1.00
Item #24: There are many things we did as a family that we can't do now	7/7 = 1.00
Item #25: Right now, we are no longer the family we were	7/7 = 1.00
Item #3: Because of our relative's illness, we can't do the things that other families do	6/7 = 0.86
Item #4: Our relative is healthy in body and mind*	6/7 = 0.86
Item #8: For our family to be really well, our family will have to go through a change	6/7 = 0.86
Item #9: "Once a mental patient, always a mental patient"	6/7 = 0.86
Item #10: Once having been hospitalized, there is a good chance of it happening again	6/7 = 0.86
Item #23: I fear that my family might have to provide financial support indefinitely	6/7 = 0.86
Item #6: At some point in time, our relative will not need psychiatric medications*	5/7 = 0.71
Item #15: My relative really does not need psychiatric care at all*	5/7 = 0.71
Item #16: Our relative will always have to take psychiatric medicine	5/7 = 0.71
Item #19: I am afraid of losing my mind	5/7 = 0.71
Item #22: It is good for our relative to stay in hospital for a long time	5/7 = 0.71
Item #28: Our relative's mind is normal*	5/7 = 0.71
Item #29: Our relative will be able to find work in the very near future*	5/7 = 0.71
Item #30: We are basically the same family we were before our relative became ill*	5/7 = 0.71
Item #1: Our family manages as well as most families do*	4/7 = 0.57
Item #26: Our relative can look forward to being married or having a steady partner*	4/7 = 0.57
Item #27: I expect my relative to be well in the future*	4/7 = 0.57

¹For each item, the I-CVI was computed as the number of participants giving a rating of either 3 or 4 divided by the total number of participants

*Items with an asterisk beside are reversed scored

Synthesis of the I-CVI, and Domain and Item Matching

Each item of the MES-FV represents one of the five domains of the family engulfment construct. The content validity of individual items, therefore, was examined in relation to the domains of the scale. Firstly, in order to determine the proportion of items within each of the five domains of the MES-FV that were rated as being relevant to the family engulfment construct, the items were organized in terms of the five domains and, within each domain, the I-CVIs were listed from highest to lowest (see Table 6). The percentage of items within each domain that had an I-CVI of 0.86 or higher is as follows: 75% of the items in domain 1; 45% in domain 2; 50% in domain 3; 100% in domain 4; and 80% of the items in domain 5.

Secondly, in order to obtain more information about the content validity of individual items for the MES-FV, each MES-FV item was analyzed in terms of its I-CVI, as well as in terms of the percentage of participants who identified the item as corresponding to the correct domain. Evidence of the content validity of individual items was strongest for items with both an I-CVI of 0.86 or higher and a percent agreement of at least 71%. Overall, 16 of the 30 MES-FV items (#2, #3, #4, #8, #9, #10, #11, #12, #13, #14, #17, #18, #20, #23, #24 and #25) had both an I-CVI of 0.86 or higher and a percent agreement of at least 71% (see Table 6). Twenty-one items, however, had both an I-CVI of 0.71 or higher and a percent agreement of at least 71% (those listed above, as well as #15, #16, #19, #28 and #30). Three items (#5, #7 and #21) had an I-CVI of 0.86 or higher but a percent agreement of below 71%. Conversely, six items (#1, #15, #16, #19, #28 and #30) had a percent agreement of at least 71% but an I-CVI of below 0.86. Only five of the 30 MES-FV items (#6, #22, #26, #27 and #29) had both an I-CVI of below 0.86 and a percent agreement of below 71%. All five of these items belong to the second domain of the scale (permanence) and four of them are reversed scored. These five items include the

following: 1) item #6: at some point in time, our relative will not need psychiatric medications (reversed scored); 2) item #22: it is good for our relative to stay in hospital for a long time; 3) item #26: our relative can look forward to being married or having a steady partner (reversed scored); 4) item #27: I expect my relative to be well in the future (reversed scored); and 5) item #29: our relative will be able to find work in the very near future (reversed scored).

Table 6

I-CVIs, and Domain and Item Matching

Domains and corresponding items	I-CVI	Percent agreement
Domain 1: A family member's sense that they and their family have changed		
Item #25	1.00	100%
Item #14	1.00	86%
Item #20	1.00	71%
Item #24	1.00	71%
Item #21	1.00	57%
Item #8	0.86	71%
Item #19	0.71	86%
Item #30*	0.71	71%
Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent		
Item #11	1.00	86%
Item #5	1.00	57%
Item #9	0.86	100%
Item #10	0.86	100%
Item #23	0.86	86%
Item #16	0.71	86%
Item #6*	0.71	57%
Item #22	0.71	57%
Item #29*	0.71	57%
Item #26*	0.57	57%
Item #27*	0.57	43%
Domain 3: The family member's acceptance of their relative's mentally ill label		
Item #2	1.00	86%
Item #4*	0.86	86%
Item #28*	0.71	100%
Item #15*	0.71	86%
Domain 4: A loss of normal roles for family members		
Item #17	1.00	100%
Item #12	1.00	71%
Domain 5: Negatively comparing one's family to other families		
Item #18	1.00	100%
Item #13	1.00	86%
Item #7	1.00	57%
Item #3	0.86	71%
Item #1*	0.57	71%

*Items with an asterisk beside are reversed scored

Summary of the Results

Seven individuals with clinical expertise in mental health/psychiatry who have worked specifically with families of individuals with schizophrenia comprised the sample for this study.

Furthermore, this study employed three strategies to assess the content validity of the MES-FV:

1) evaluation of the family engulfment construct and the five domains of the MES-FV, 2) evaluation of the correspondence of the MES-FV items to the MES-FV domains, and 3) evaluation of each MES-FV item in terms of its relevance to the family engulfment construct.

Two case studies were used to evaluate the family engulfment construct and the five domains of the MES-FV. There was 100% agreement for all five domains of the MES-FV for the second of the two case studies. The participants had some difficulty, however, identifying the presence of domain 2 (permanence) and the absence of domain 4 (role loss) in the first of the two case studies.

Domain and item matching was used to evaluate the correspondence of the MES-FV items to the MES-FV domains. Overall, 22 of the 30 MES-FV items achieved a percent agreement of at least 71%. In general, a pattern seemed to emerge in which participants incorrectly identified some of the items corresponding to domain 2 (permanence) as corresponding to domain 3 (illness acceptance). Similarly, a pattern seemed to emerge in which participants incorrectly identified some of the items corresponding to domain 5 (negative comparisons) as corresponding to domain 4 (role loss), and vice versa.

Finally, the content validity index (CVI) was used to evaluate each MES-FV item in terms of its relevance to the family engulfment construct. Overall, 19 of the 30 MES-FV items had I-CVIs of 0.86 or higher. Twenty-seven items, however, had I-CVIs of at least 0.71. Of the three items that had I-CVIs of 0.57 (#1, #26 and #27), all of them are reversed scored and two of

them (#26 and #27) belong to the second domain (permanence) of the scale. Moreover, the S-CVI/Ave for the MES-FV was 0.85.

The data that emerged from the three strategies which were employed to assess the content validity of the MES-FV were synthesized to provide more information about the content validity of the scale. Overall, 21 of the 30 MES-FV items had both an I-CVI of 0.71 or higher and a percent agreement of at least 71%. Only five items (#6, #22, #26, #27 and #29) had both an I-CVI of below 0.86 and a percent agreement of below 71%. All five of these items belong to the second domain of the scale (permanence) and four of them (#6, #26, #27 and #29) are reversed scored.

Chapter VI – Discussion

The purpose of the present study was to contribute to the psychometric evaluation of the MES-FV, specifically, its content validity, as a first step toward providing a standardized family engulfment measure that would assess the impact of schizophrenia on a family member's self-concept and on the identity of the family as a whole. As previously stated, the most widely used method of quantifying content validity among nurse researchers is the content validity index (CVI) (Polit & Beck, 2006; Polit et al., 2007). In addition to the item-level and scale-level CVI, case studies, and domain and item matching were also used to evaluate the content validity of the MES-FV. The discussion that follows begins with a consideration of the panel of experts who participated in the study. The discussion is then organized according to the data collection methods which were developed to evaluate the content validity of the MES-FV. Lastly, conceptual issues emerging from the results will be discussed.

The Panel of Experts

In order to compute the item-level CVI, or I-CVI, a panel of experts was asked to rate each MES-FV item in terms of its relevance to the family engulfment construct. According to the literature on content-related validity evidence, this panel might include individuals with expertise in various fields, for example, individuals with knowledge of instrument development, those with clinical expertise in a discipline relevant to the content area and those with expertise in another appropriate field of practice (Burns & Grove, 2009). In the present study, content validity testing was conducted in a sample of seven healthcare professionals, six nurses and one social worker, who examined the MES-FV for content relevance. Professionals were invited to participate in the study based on their known experience working with families of individuals with schizophrenia. The strength of the review panel is evident, given that it included health care

professionals with an average of 16 years in mental health/psychiatry and an average of more than 12 years of experience working with families.

Although nine nurses and four social workers were invited to participate in the study, all of the participants who completed the evaluation packages were nurses with the exception of one. Given that it is recommended to seek out individuals with expertise in various fields (Burns & Grove, 2009), the fact that the panel of experts included individuals with expertise primarily in the field of nursing is a potential limitation of the study. Perhaps experts from other disciplines would offer further clarity regarding the findings of the study. Furthermore, it is recommended that individuals be sought out who possess knowledge of instrument development as well as content expertise (Burns & Grove). The fact that the panel of experts did not include anyone with confirmed knowledge of instrument development is another potential limitation of the study which might help to explain the difficulty that some of the participants had with the reversed scored items. Moreover, the expert review panel for conducting the content validity testing in some other content validity studies has included both health care professionals and members of the population for whom the scale was intended (Johnson & Rogers, 2006). The absence of family members on the expert review panel for conducting the content validity testing in the present study may be considered an additional limitation. Despite these potential limitations, a decision was made to seek out clinicians with content expertise as a logical first step in examining the content validity of the MES-FV. It was presumed that, as a first step, clinicians would be best suited to complete the evaluation tasks as they would not only possess knowledge of the experiences of different families of individuals with schizophrenia, but they would also be familiar with the underlying concepts of the family engulfment construct as they have been discussed in the literature to date.

While professionals were invited to participate in the study based on their known experience working with families of individuals with schizophrenia, it is not known whether the participants who completed the evaluation packages had experience working mostly with long-term or first-episode clients and their families. The degree to which family members see their relative's illness as relatively permanent is conceptualized as a component of family engulfment. There are a number of items on the MES-FV, therefore, dealing with the perception of illness permanency. Despite being provided with a description of the family engulfment construct along with the domains of the MES-FV, it is possible that the experts' relevance ratings for certain items might have been influenced by whether they themselves held a more chronic view or a more optimistic view of the illness. As Polit et al. (2007) point out in their discussion of the content validity index, "...what if, for example, one expert...had a biased viewpoint?" (p.495). Furthermore, it is reasonable to assume that whether participants held a more chronic view or a more optimistic view of the illness might be accounted for, at least in part, by their clinical experience. For example, participants who have worked mostly with long-term clients might hold a more chronic view of the illness, while participants who have worked mostly with first-episode clients might hold a more optimistic view. Participants were not asked whether they had experience working mostly with long-term or first-episode clients and their families. In retrospect, it would have been interesting to have been able to compare the results in this regard.

The Content Validity Index

The item-level content validity index.

Once again, the most widely reported measure of content validity among nurse researchers is the content validity index (Polit & Beck, 2006; Polit et al., 2007). A CVI value was computed for each item on the MES-FV in order to help draw conclusions about the scale's

quality. Using the I-CVI alone as a measure of the content validity of individual items, there is strong evidence of content validity for the majority of the MES-FV items. There were 19 items with I-CVIs of either 1.0 or 0.86, such that 19 items were rated as being relevant by at least six of the seven participants. Furthermore, there were eight items with I-CVIs of 0.71; eight items were rated as being relevant by five of the seven participants. Taking into account the risk of chance disagreements, as well as non-chance disagreements if a participant was biased or had misunderstood the construct specifications provided (Polit et al., 2007), an I-CVI of 0.71 is arguably still considered moderate evidence of content validity for seven experts/participants. Finally, using the I-CVI alone as a measure of the content validity of individual items, there is weak evidence of content validity for only a small number of the MES-FV items. There were only three items with I-CVIs of 0.57. Specifically, three items were rated as being relevant by only four of the seven participants. These three items include the following: 1) item #1: our family manages as well as most families do; 2) item #26: our relative can look forward to having a steady partner; and 3) item #27: I expect my relative to be well in the future. The initial I-CVIs for these three items suggest the need to revisit the description of the family engulfment construct and the domains of the MES-FV provided to the participants, as well as the instructions to the participants regarding the rating task (Polit & Beck, 2006). It is noteworthy that all three of these items, as well as five of the eight items for which there is only moderate evidence of content validity, are reversed scored. This finding suggests that perhaps the participants had some difficulty with the reversed scored items. That the participants had some difficulty with the reversed scored items is suggested further by the fact that only one of the 19 items for which there is strong evidence of content validity is reversed scored. Perhaps the instructions to the participants might have included a more detailed explanation of reversed scoring. It is not

anticipated, however, that the reversed scored items would pose a problem for family members who would be filling out the scale as they would not be asked to rate each MES-FV item in terms of its relevance to the family engulfment construct, but only to rate how true or false each statement or item is for them.

The scale-level content validity index.

In order to help draw conclusions about the quality of the MES-FV, a CVI value was also computed for the overall scale. While the S-CVI/UA for the MES-FV was only 0.43, far from the recommended minimum S-CVI of .80 (Davis, 1992), the S-CVI/Ave for the MES-FV was 0.85, much closer to the recommended minimum S-CVI/Ave of .90 (Waltz, Strickland & Lenz, 2005). At first glance, an S-CVI/UA of 0.43 is somewhat discouraging. As suggested by others, however, perhaps the universal agreement calculation method is overly stringent, especially when there are seven experts on the validation panel (Polit & Beck, 2006). Furthermore, demanding 100 percent agreement ignores the risk of chance disagreements, not to mention non-chance disagreements if one of the participants was biased or had misunderstood the description of the family engulfment construct which was provided (Polit et al., 2007). The S-CVI/Ave is the preferable method for calculating the scale-level CVI for the MES-FV not only because it avoids these problems but also because it reflects the performance of each MES-FV item through the averaging feature (Polit et al.). While the MES-FV did not achieve an S-CVI/Ave of .90 or higher, perhaps if the three items with unacceptable I-CVIs (items #1, #26 and #27) were re-evaluated by a panel of experts with clearer instructions, this would not be a difficult standard to meet.

Case Studies

In addition to the CVI, case studies were also used to evaluate the content validity of the MES-FV. In general, the participants were able to correctly identify each of the five domains of the MES-FV as being either present or absent in each of the two case studies. This finding supports the distinguishability of the domains of the MES-FV.

The participants had some difficulty, however, identifying the presence of the second domain (permanence) in the first of the two case studies. The presence of the second domain in the first case study about a family who is experiencing a first episode of schizophrenia is illustrated by the following excerpt:

Different doctors have told Eve and Rick that schizophrenia is a chronic illness marked by exacerbations and remissions. While they accept that Alex has schizophrenia, stories about other young people who have recovered well from a first episode of schizophrenia offer them a sense of hope. Eve and Rick are grateful that the risperidone seems to be helping Alex and look forward to a point in time when he will not need antipsychotic medication. When this time comes, Eve and Rick hope that their family will go back to normal. (Appendix C)

The presence of the second domain in the case study is illustrated by positively worded statements reflecting the parents' sense of hope for a better future for their son, in keeping with the MES-FV reversed scored items belonging to the second domain of the scale (specifically items #6 and #27). The description of the second domain of the MES-FV provided to the participants stated that "chronicity and hope are concepts highly relevant to this domain...The degree to which family members perceive illness permanency is also reflected in whether or not they are able to remain hopeful for a better future for their ill relative" (Appendix B).

Furthermore, the participants were reminded that “there are several items of the MES-FV that are reversed scored” (Appendix C). Still, more than half of the participants mistakenly identified the second domain as being absent in the case study. This finding suggests that, just as the participants had some difficulty with the reversed scored items, perhaps they also had some difficulty with the positively worded statements reflecting the inclusion of varying degrees of engulfment within the family engulfment construct. It is also conceivable, however, that these positively worded statements were misinterpreted as illustrating another domain of the MES-FV, specifically the third domain (illness acceptance) of the scale. This possibility will be considered further at a later point in the discussion.

The participants also had some difficulty identifying the absence of the fourth domain (role loss) in the first of the two case studies; more than half of them mistakenly identified the fourth domain as being present in the case study. This finding is most likely related to the fact that the loss of normal roles for family members is often implied in schizophrenia. For instance, in the study by Magliano et al. (2005) exploring burden and social networks in families of patients with schizophrenia versus long-term physical disorders, the authors found that schizophrenia appeared different from the other groups in several aspects. Specifically, social network was found to be significantly weaker in the schizophrenia group (Magliano et al.). Furthermore, there was a clear relationship between a reduction in the relatives’ social network and increased levels of burden only in the schizophrenia group (Magliano et al.). Rolland (1987), whose work is in arena of physical illness, particularly chronic disease, provides a conceptual framework for thinking about the impact of chronic illness on the family life cycle and points out that “the ability of the family to maintain the semblance of a normal life under the ‘abnormal’ presence of a chronic illness...is a key task...” (p.207). The ability of the family to maintain the

semblance of a normal life is determined, at least to some extent, by the ability to maintain normal roles, including social roles. As Rudge and Morse (2004) argue, however, families living with schizophrenia are not “viewed as capable of sustaining meaningful relationships outside of the community of sufferers and caregivers” (p.7). Perhaps the loss of normal roles for family members is not only implicit but nearly inescapable in schizophrenia, as demonstrated by the fact that the participants identified role loss as being illustrated in the case study when it was not.

Domain and Item Matching

Domain and item matching was also used to evaluate the content validity of the MES-FV. Overall, 22 of the 30 MES-FV items achieved a percent agreement of at least 71%; 22 of the 30 MES-FV items were identified by at least five of the seven participants as corresponding to the correct domain. This finding further supports the distinguishability of the domains of the MES-FV. Of the eight MES-FV items that did not achieve a percent agreement of at least 71%, six of them (items #5, #6, #22, #26, #27 and #29) belong to the second domain of the MES-FV (permanence), and four of these (#6, #26, #27 and #29) are reversed scored. This finding suggests, once again, that perhaps the participants had some difficulty with the reversed scored items. Furthermore, this finding suggests that perhaps the participants had some difficulty with the items belonging to the second domain of the scale, consistent with the findings from the first of the two case studies.

In general, a pattern seemed to emerge in which participants incorrectly identified some of the items corresponding to domain 2 (permanence) as corresponding to domain 3 (illness acceptance). The most obvious example concerns item #27: “I expect my relative to be well in the future”; *all four* participants who did not choose domain 2 chose domain 3 instead. Similarly, a pattern seemed to emerge in which participants incorrectly identified some of the items

corresponding to domain 5 (negative comparisons) as corresponding to domain 4 (role loss), and vice versa. For example, for item #7: "Our friends and family see us only as a family with problems," *all three* participants who did not choose domain 5 chose domain 4 instead. These findings warrant a closer consideration of the second and third domains, as well as the fourth and fifth domains of the MES-FV.

The second and third domains of the MES-FV.

Perceiving illness permanency is the primary focus of the second domain of the MES-FV. The second domain of the MES-FV includes items which reflect a perception of illness permanency, as well as reversed scored items which reflect a sense of hope regarding the permanency of the illness. On the other hand, the primary focus of the third domain of the MES-FV is illness acceptance. The third domain of the MES-FV includes items which reflect the acceptance of mental illness, as well as reversed scored items which reflect the denial of mental illness.

A closer consideration of the second and third domains of the MES-FV suggests that some of the items reflecting a perception of illness permanency were misinterpreted as reflecting the acceptance of mental illness. Specifically, for item #22: "It is good for our relative to stay in hospital for a long time," *all three* participants who did not choose domain 2 chose domain 3 instead. A closer consideration of these domains also suggests that some of the reversed scored items reflecting a sense of hope regarding the permanency of the illness were misinterpreted as reflecting the denial of mental illness. Specifically, for item #6: "At some point in time, our relative will not need psychiatric medication," *all three* participants who did not choose domain 2 chose domain 3 instead. Furthermore, as mentioned above, for item #27: "I expect my relative to be well in the future," *all four* participants who did not choose domain 2 chose domain 3

instead. These findings are in keeping with the suggestion above that, for the first case study, perhaps the positively worded statements illustrating the presence of the second domain in the case study were misinterpreted as illustrating the third domain of the scale. The most likely explanation for these findings concerns the issue of chronicity in schizophrenia. If, for example, one participant had a biased viewpoint and held a more chronic view of schizophrenia, believing that the illness and its sequelae are relatively permanent, it stands to reason that they might interpret a perception of illness permanency as being indicative of the acceptance of mental illness. It also stands to reason that they might interpret a sense of hope as being indicative of the denial of mental illness. These findings call into question the views held by the participants in this study, and perhaps mental health clinicians in general, regarding chronicity and the possibility of recovery in schizophrenia. The issue of chronicity and recovery in schizophrenia will be considered further at a later point in this discussion. These findings also suggest that perhaps the description of the second and third domains of the MES-FV could be modified in the future to provide further differentiation between illness permanence and illness acceptance. In conjunction with a review of the domains, it may also be worthwhile to review the items belonging to the second and third domains of the scale.

The fourth and fifth domains of the MES-FV.

The primary focus of the fourth domain of the MES-FV concerns the loss of normal roles for family members. Specifically, items of the scale corresponding to the fourth domain are concerned with the social isolation and loss of social roles experience by family members. The primary focus of the fifth domain of the MES-FV concerns the negative comparisons that families living with schizophrenia make to other families. Items of the scale corresponding to the fifth domain include statements about those ways in which families who have a member with

schizophrenia see themselves differently from other families because of their relative's illness and also perceive that others see them differently.

The most likely explanation for the apparent confusion between the fourth and fifth domains of the MES-FV is that the participants themselves may see families who have a member with schizophrenia as being different from other families, in large part due to the loss of social roles. In the qualitative study by Rudge and Morse (2004) into the lives of relatives and partners of people with schizophrenia, participants spoke of a tendency for their families to exist within a subculture and community of sufferers and caregivers. Similarly, in the study by Karp and Tanarugsachock (2000) exploring how caregivers manage their emotions over time, one participant commented that she "[didn't] identify with normal people anymore" (p.18), and another spoke of living "in the nation of the wounded" (p.18). The intrinsic nature of the loss of social roles for family members is also echoed in the suggestion above that, for the first case study, more than half of the participants mistakenly identified the fourth domain as being present in the case study, most likely related to the fact that the loss of normal roles for family members is often implied in schizophrenia. The social isolation and loss of social roles experienced by family members will also be considered further at a later point in this discussion.

Synthesis of the I-CVI, and Domain and Item Matching

The data that emerged from the data collection methods which were used to evaluate the content validity of the MES-FV were synthesized to provide more information about the content validity of the scale. In other words, each MES-FV item was analyzed in terms of its I-CVI, as well as in terms of the percentage of participants who identified the item as corresponding to the correct domain. Evidence of the content validity of individual items was strongest for items with both an I-CVI of 0.86 or higher and a percent agreement of at least 71%. Overall, 16 of the 30

MES-FV items had both an I-CVI of 0.86 or higher and a percent agreement of at least 71%. Twenty-one items, however, had both an I-CVI of 0.71 or higher and a percent agreement of at least 71%, providing solid evidence of the content of individual items, as well as the content validity of the overall scale. As discussed above, there were only three items (#1, #26 and #27) with I-CVIs of 0.57, and two of these items (#26 and #27) also had a percent agreement of below 71%, suggesting even more so the need for item improvements.

Only five of the 30 MES-FV items (#6, #22, #26, #27 and #29) had both an I-CVI of below 0.86 and a percent agreement of below 71%. It is noteworthy that four of these items (#6, #26, #27 and #29) are reversed scored, suggesting, yet again, that perhaps the participants had some difficulty with the reversed scored items. It is also noteworthy that all five of these items belong to the second domain of the MES-FV (permanence), suggesting, once again, that perhaps the participants had some difficulty with the items belonging to the second domain of the scale. More specifically, all five of these items were misidentified by two or more of the seven participants as corresponding to the third domain (illness acceptance) of the scale.

Chronicity and Recovery in Schizophrenia

The findings of the present study call into question the views held by the participants in this study, and perhaps mental health clinicians in general, regarding chronicity and the possibility of recovery in schizophrenia. Traditionally, schizophrenia has been viewed as a chronic condition with a very pessimistic outlook (Bellack, 2006). Recent studies, however, have challenged both the traditional perspective on the course of illness and the associated assumptions about the capacity of people living with schizophrenia to lead a productive and satisfying life (Bellack). Long-term studies suggest that as many as 50% of people with schizophrenia have good outcomes (Harrison et al., 2001; Harrow, Grossman, Jobe & Herbener,

2005). Furthermore, in the study by Romano (2009) looking at the process of recovery from a first episode of schizophrenia, participants' sense of self, although "reshaped," seemed to endure throughout their recovery. Studies with both chronic and recent onset patients suggest that schizophrenia has a heterogeneous course, which can be favorably influenced by comprehensive and continuous treatment as well as personal factors such as family support (Lieberman, Kopelowicz, Ventura & Gutkind, 2002).

The nature and quality of family support are likely impacted by whether family members are able to remain hopeful for a better future for their ill relative. In the study by Tuck et al. (1997) which explored the experience of caring for an adult child with schizophrenia, participants spoke of hope as a sustaining force that made it possible to seek ways to improve day to day life for their child and themselves. As Onken, Craig, Ridgway, Ralph and Cook (2007) point out in their analysis of the definitions and elements of recovery: "Hope is central to recovery...one's own and other's hopefulness has been identified as critical in launching the journey from despairing about a life situation to hoping for a better future" (p11). Hope may be expressed by someone in the individual's natural support network, such as a family member, or their formal support network, such as a mental health professional (Onken et al.). Despite the fact that this relatively "new conception of the illness" (Bellack, 2006, p.432) is supported by both long-term and first episode studies, to what extent do mental health clinicians embrace the concept of recovery? According to Kelly and Gamble (2005), many mental health professionals now claim to embrace the concept of recovery yet fail to make the desired impact upon the care and treatment of individuals with schizophrenia. Perhaps the nature, quality and impact of professional support are determined not only by whether mental health professions embrace the

concept of recovery, but also by the extent to which they live it in their practice through conveying a hopeful message to patients and their families.

The findings of the present study highlight the importance of understanding the views held by mental health clinicians regarding the possibility of recovery in schizophrenia, how these views are communicated to patients and their families, the potential impact of these views on an individual's recovery process and on the engulfment of their family members, as well as opportunities for change. Participants in the present study were not invited to provide written comments that might have shed further light on their views. Perhaps in future research related to the continued psychometric evaluation of the MES-FV, participants would be invited to provide such insights.

Role Loss in Schizophrenia

Another conceptual issue emerging from the results of the present study concerns the loss of normal roles for family members that seems to be implicit in schizophrenia. The literature suggests that this loss of normal roles occurs in two ways. Firstly, it occurs through what Estroff (1989) called progressive role restriction. As family members focus their time and attention on their ill relative, withdraw from social, leisure and work activities, and lose contact with friends and extended family (Brady & McCain, 2004; Magliano et al., 2005; Rudge & Morse, 2004; Tsang et al., 2003), they also lose valued social roles and the acceptable identities derived from those roles. Secondly, the loss of normal roles is also a consequence of stigma and the social isolation of family members (Tsang et al.). In a recent study by Buizza et al. (2007) which sought to identify the constituent elements of the stigma of schizophrenia from the perspective of patients and their relatives, access to social roles was one of the four dimensions of stigma which were identified. Relatives' social ties were affected by the stigma of schizophrenia; they

experienced abandonment by their relatives and friends who felt uneasy with them (Buizza et al., 2007). The results of the study by Magliano et al. comparing family burden in schizophrenia versus long-term physical disorders highlight the need to provide families with supportive interventions, including the reinforcement of relatives' social networks, "especially in the case of schizophrenia" (p.313).

As previously stated, for the domain and item matching, the most likely explanation for the apparent confusion between the fourth (role loss) and fifth (negative comparisons) domains of the MES-FV is that the participants themselves may see families who have a member with schizophrenia as being different from other families, in large part due to the loss of social roles. For example, for item # 7: "Our friends and family see us only as a family with problems," *all three* participants who did not choose domain 5 chose domain 4 instead. Similarly, for #12: "We can only be friends with other families who have mentally ill relatives," *both* participants who did not choose domain 4 chose domain 5 instead. These participants' responses reflect the possible likelihood that they were not attending to the full experience of families living with schizophrenia, which includes the experience of stigma as much as role loss. Furthermore, their responses highlight the need to better understand the perspectives of mental health clinicians with regard to the experiences of families who have a member with schizophrenia.

Summary

Based on the findings of this study, to what extent does the MES-FV include all the major elements relevant to the family engulfment construct? Each item of the MES-FV represents one of the five domains of the family engulfment construct. While the CVI provides information about the 30 MES-FV items, it does not provide direct information about the five MES-FV domains. Case studies were used to evaluate the domains of the MES-FV. Domain and

item matching was also used to evaluate the fit between the domains and the items of the scale. Finally, the data that emerged from the I-CVI, and domain and item matching were synthesized to provide more information about the content validity of the scale. In order to obtain more information about the content validity of individual items for the MES-FV, whether or not each MES-FV item was rated as being relevant to the family engulfment construct was compared with whether or not the item was also identified as corresponding to the correct domain. The findings of the study seem to suggest strong evidence of content validity for the MES-FV. The findings also suggest an evident fit between the conceptual definitions of the domains of the MES-FV and the items of the scale reflecting those domains.

Chapter VII – Implications and Conclusion

This study has demonstrated evidence for the content validity of the Modified Engulfment Scale – Family Version (MES-FV), and lends support for the possible future use of the MES-FV in research and clinical practice following further psychometric testing. The results of the present study suggest several important implications for nursing practice and education, as well as nursing research. Furthermore, this study also suggests important theoretical implications related to the concept of family engulfment, as well as the use of the CVI as an indicator of content validity.

Nursing Practice & Education

The construct of family engulfment offers a perspective for understanding how a family member's self-concept and how a family's identity may incorporate the experience of mental illness. Furthermore, the construct of family engulfment provides a theoretical base that supports the development of new therapeutic interventions designed to assist family members to achieve a positive self-concept and family identity within the context of a severe mental illness such as schizophrenia. The challenge for clinicians is to discover methods that enable families of individuals with schizophrenia to actively engage in defining their own illness experience. The MES-FV is potentially a clinically relevant measure that may provide direction for clinical interventions that are geared toward minimizing family engulfment and maximizing the healthier aspects of family life. The MES-FV may also provide an instrument for monitoring and evaluating the progress of therapeutic programs for families.

While it is important for clinicians to discover methods that enable individuals with schizophrenia and their family members to actively engage in defining their own illness experience, it is also important for clinicians to recognize the influence that they might have in

shaping how individuals and family members might define their illness experience. The literature suggests, for instance, that “statements made by mental health professionals that express the supposed chronic nature of the illness and profess limited prospects in life can be detrimental to an individual’s recovery process” (Onken et al., 2007, p.11). Furthermore, the literature suggests that family members’ concerns about their ill relative are formulated with the perception that “mental health professionals do not offer hope” (Rudge & Morse, 2004. p.7). The results of the present study suggest that consideration needs to be given to understanding the views held by clinicians regarding chronicity and the possibility of recovery in schizophrenia. As Kelly and Gamble (2005) point out, mental health nurses need to give hope to people with schizophrenia and their family members “that they can recover, and assist in the provision of opportunities to enable this to happen” (p.250). The family engulfment construct offers a perspective for understanding the importance of hope for families of individuals with schizophrenia and provides a theoretical base that supports the need to provide these families with a message of hope regarding the possibility of recovery in schizophrenia.

The results of the present study also highlight the seemingly implicit nature of the loss of social roles for family members of individuals with schizophrenia. Clinicians, therefore, have an important role to play in providing the families of those with schizophrenia with supportive interventions, including the reinforcement of relatives’ social networks (Magliano et al., 2005). While the loss of social roles is of paramount importance for family members, the results of the present study also suggest that clinicians are at risk of placing so much importance on the loss of social roles that they might miss opportunities to attend to other socio-psychological sequelae, such as stigma. The family engulfment construct, however, provides clinicians with an

informative perspective that facilitates an understanding of the full range of socio-psychological sequelae associated with being a family member of an individual with schizophrenia.

Nursing Research

The study findings suggest many avenues for future research. Of the utmost importance is the continued psychometric assessment of the MES-FV. Given the preliminary nature of this study, it will be necessary to assess the construct validity of the MES-FV as well. The aim will be to test hypotheses pertaining to the relationship of family engulfment to related concepts such as hopelessness, stigma, role loss and burden. While the study findings support both the interconnectedness and distinguishability of the domains of the MES-FV, it will also be necessary to perform factor analysis, which is a grouping technique that allows for evaluation of the dimensionality of scales (Munro, 2001; Nunnally & Bernstein, 1994). Factor analysis could be performed to examine relationships among the various items of the MES-FV, and to establish whether the MES-FV is composed of several conceptual dimensions or whether it is a homogeneous scale.

Further research is required to better understand the relationship between family engulfment and individual engulfment. In McCay's (1994) study assessing the construct validity of the MES, the hypothesis that the family's ratings of the engulfment of their relative would be correlated with their relative's MES scores was not confirmed, indicating that perhaps the family perspective of engulfment differs from that of the individual. Those with schizophrenia viewed themselves less negatively than did their family members (McCay). McCay raises the possibility that "the family's ratings of engulfment may have captured the family's own sense of engulfment rather than the engulfment level of their relative" (p.96). Future research is required to enable the

comparison of family and individual perspectives of engulfment, and to better understand the interactive nature of the engulfment process between the individual and the family.

Future research is also required to compare first-episode and long-term perspectives of family engulfment. It is anticipated that families living with schizophrenia for a longer period of time would experience greater levels of engulfment, in large part due to a presumed sense of permanence and loss of normal roles over time. According to Rolland (1987), however, during the crisis phase of a chronic illness, the family needs to "grieve for the loss of the pre-illness family identity" (p.207), as well as "move toward a position of acceptance of permanent change" (p.207), both of which are reflected in the family engulfment construct. It is conceivable, therefore, that families experiencing a first episode of schizophrenia could initially experience high levels of engulfment as well, thus further highlighting the need for clinicians to provide these families with a message of hope regarding the possibility of recovery in schizophrenia.

Lastly, future research is required to better understand the views of clinicians with regard to the experiences of families of individuals with schizophrenia. The results of the present study suggest that some clinicians may possibly view schizophrenia as a chronic condition with a very pessimistic outlook. The results also suggest that some clinicians may place much importance on the loss of social roles for family members, potentially to the exclusion of other factors which may impact and challenge family members. In the present study, clinicians were not invited to provide written comments which may have provided further insights into their views. In future studies contributing to the psychometric evaluation of the MES-FV, it would be beneficial to invite clinicians to provide such comments.

This study has demonstrated sufficient evidence for the content validity of the MES-FV. Its use in research and clinical practice, however, can not be recommended at this time. Perhaps

further psychometric testing will yield sufficient information concerning the reliability and validity of the MES-FV such that it use in clinical practice and research can be recommended.

Theoretical Implications

The construct of family engulfment offers a perspective for understanding how a family member's self-concept and how a family's identity may incorporate the experience of mental illness. It is postulated that a transformation of self-concept and family identity occur through a process of family engulfment, in which family members see themselves and their family completely and merely in terms of their relative's illness. Despite the preliminary nature of this study, an investigation of the content validity of the MES has provided support for the theoretical construct of family engulfment through the examination of the items and domains of the scale by a panel of experts. Future research into the validity of the MES-FV might include validation of the domains of the scale.

The pattern that seemed to emerge in which participants incorrectly identified some of the items corresponding to the second domain of the MES-FV (permanence) as corresponding to the third domain of the scale (illness acceptance) has implications for our theoretical understanding of family engulfment. Specifically, these findings suggest a close relationship between illness permanence and illness acceptance in the minds of the experts who participated in the study, in which a perception of illness permanency was understood as reflecting the acceptance of mental illness and a sense of hope was understood as reflecting the denial of illness. Hence, these findings suggest a need to clearly differentiate between illness permanence and illness acceptance within the family engulfment construct as the literature suggests that schizophrenia may not be a chronic condition (Bellack, 2006; Liberman et al., 2002). As Bellack

points out, "schizophrenia has traditionally been viewed as a chronic condition with a very pessimistic outlook, but that assumption may not be valid" (p.432).

The final issue warranting discussion concerns how evidence of content validity was provided in the present study, and whether the content validity index (CVI) alone is an acceptable indicator of content validity. While validity has been discussed in the literature in terms of three primary types (content validity, predictive validity and construct validity), content validity and predictive validity are now considered evidence of construct validity (Burns & Grove, 2009). Construct validity "examines the fit between the conceptual definitions and operational definitions of variables" (Burns & Grove, 2005, p.217) and content validity "examines the extent to which the method of measurement includes all the major elements relevant to the construct being measured" (Burns & Grove, 2009, p.381). Scale developers have typically provided evidence of content validity by computing a CVI using ratings of item relevance by content experts (Polit & Beck, 2006; Polit et al., 2007). If content validity is now considered evidence of construct validity, to what extent do experts' ratings of item relevance provide evidence of "the fit between the conceptual definitions and operational definitions of variables"? In other words, to what extent do experts' ratings of item relevance provide evidence of the fit between the domains and the items of a scale?

The first step of instrument development is to identify what is to be measured, referred to as the domain of the construct (Burns & Grove, 2009). Once the domain is determined, items for the instrument that represent the domain of the construct are developed or selected (Burns & Grove, 2009). When there is more than one domain to be measured, it stands to reason that evidence of content validity should be provided, not only by evaluating each scale item in terms

of its relevance to the underlying construct, but also by evaluating each scale item in terms of its relevance to the domain of the construct which it is intended to represent.

Each item of the MES-FV represents one of the five domains of the family engulfment construct. While the CVI provides information about the 30 MES-FV items, it does not provide direct information about the five MES-FV domains. Case studies were used to evaluate the domains of the MES-FV. Domain and item matching was also used to evaluate the fit between the domains and the items of the scale. Finally, the data that emerged from the I-CVI, and domain and item matching were synthesized to provide more information about the content validity of the scale. The case studies, and domain and item matching provided valuable insights into the content validity of the MES-FV, insights that could not have been gained from using the CVI alone, suggesting perhaps that such data collection methods be used in addition to the CVI to assess content validity in future studies.

Conclusion

This study was designed to assess the psychometric properties of the MES-FV, specifically the content validity of the scale. Given the preliminary nature of this study, it will be necessary to assess the construct validity of the MES-FV as a next step toward providing a standardized family engulfment measure that would assess the impact of schizophrenia on a family member's self concept and on the identity of the family as a whole. It is evident from the study results, however, that there exists strong evidence concerning the content validity of the MES-FV. The MES-FV, in conjunction with the construct of family engulfment, look promising in terms of their usefulness in providing directions for clinical interventions and future research designed to improve the quality of life for families of individuals living with schizophrenia.

Appendix A: Letter of Information for a Research Study

Title: "The Content Validity of the Modified Engulfment Scale – Family Version"

Dear Expert,

We are looking for expert nurses, case managers and social workers to participate in the evaluation of the Modified Engulfment Scale – Family Version (MES-FV) for the purposes of examining the content validity of the scale. This study is being conducted by Andria Aiello, Dr. Elizabeth McCay and Dr. Heather Beanlands from the School of Nursing at Ryerson University, and Dr. Donna Romano from Mount Sinai Hospital in Toronto, Ontario.

This instrument would allow clinicians to assess the degree to which family members of individuals with schizophrenia define themselves and their family by their relative's illness, and subsequently provide directions for interventions designed to improve the quality of life for these family members.

If you choose to participate, you will be asked to fill out the enclosed evaluation package. First, to evaluate the proposed family engulfment construct and the domains of the MES-FV, you will be provided with a description of the proposed family engulfment construct, as well as a description of each of the five domains of the MES-FV (Appendix B). You will also be provided with two case studies, and each case study will illustrate two or more of the five domains of the MES-FV. For each case study, you will be asked to indicate whether each of the five domains is present or absent (Appendix C). Second, to evaluate the relevance of the MES-FV items to the MES-FV domains, you will be provided with a list of the 30 items and a list of the five domains that compose the MES-FV, and you will be asked to match each item to its domain (Appendix D). Third, to evaluate the content validity of the MES-FV, you will be asked to rate each scale item in terms of its relevance to the family engulfment construct (Appendix E).

We will also ask you to provide some general information about your experience as a nurse, case manager or social worker, such as your area of practice, years in the specialty and years of experience working with families. Basic demographic information, including age and gender, will also be requested. Names will not be on evaluation packages.

We anticipate completing the evaluation package will take approximately 30 to 45 minutes of your time. Once completed, we ask you to mail the evaluation package back to us in the stamped self-addressed envelop provided within two weeks of receiving the package. You will be contacted within one week of receiving the package, and reminded to complete and return the package. Because efforts will be made to attempt to keep responses as anonymous as possible, withdrawal of your responses is not possible once your evaluation has been received. Responses will be stored in a locked file for five years and then destroyed (shredded). Only the research team will have access to your responses, and only grouped responses will be used and reported at professional nursing conferences and in professional nursing journals.

Your participation in the evaluation of the MES-FV is entirely voluntary and you may choose not to fill out the evaluation package. Due to the method of recruitment and the small number of people being recruited to participant in the study, there are limitations on anonymity. The investigators, however, will attempt to keep responses as anonymous as possible and will

maintain confidentiality. Non-participation will in no way affect your future relationships and/or interactions with any person or institution involved in this study.

The investigators do not know of any harm that may arise from participating in this study. Your participation in this study will help investigators to better assess the content validity of the scale. If you experience discomfort with any questions please feel free to refuse to respond to any item in the package.

If you would like to participate, please fill out the enclosed evaluation package and, once completed, mail it back to us in the self-addressed stamped envelope. **Completion of the evaluation package and return via self-addressed stamped envelope implies your consent to participate in this study.** Please do not include any identifying information on any part of the package in order to attempt to keep your responses as anonymous as possible.

Should you require more information or have any questions, please contact Andria Aiello at aaiello@ryerson.ca or 647-990-2634.

You may also contact Dr. Elizabeth McCay, Supervisor, at bmccay@ryerson.ca or 416-979-5000 ext. 6331

The Research Ethics Board at Ryerson University approved the study. You may contact the Research Ethics Board at Ryerson University at 416-979-5000 ext. 7112.

THANK YOU FOR CONSIDERING OUR INVITATION TO PARTICIPATE IN THIS RESEARCH.

Sincerely,

Andria Aiello, RN

Appendix B: The Family Engulfment Construct and the Domains of the MES-FV

The Family Engulfment Construct

Family engulfment refers to the degree to which family members define themselves and their family by their relative's illness – schizophrenia. In other words, the construct of family engulfment offers a perspective for understanding how a family member's self-identity and how a family's identity may incorporate the experience of mental illness. It is postulated that a transformation of identity occurs through a process of family engulfment, in which family members see themselves and their family completely and merely in terms of their relative's illness. This transformation of identity involves a number of dimensions or domains, and these will be discussed below.

The Domains of the Modified Engulfment Scale – Family Version (MES-FV)

Domain 1: A family member's sense that they and their family have changed.

Both family identity and self-identity are the objects of the engulfing process for family members, and, as such, are intrinsically linked to the family engulfment construct. Integral to family engulfment, therefore, is a family member's sense that they and their family have changed. The illness has a negative impact on the emotional and psychological wellbeing of individual family members, which contributes to a family member's sense of having changed. The illness also has a negative impact on the family as a whole. As the family incorporates the experience of mental illness, there is an erosion of the pre-illness family identity. In other words, the family history becomes divided into two periods of time: the family before the illness and the family after the onset of the illness.

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent.

As family members grieve for the loss of the pre-illness family identity, they may move toward a position of perceiving permanent change. Family members may see not only the loss of the pre-illness family identity as relatively permanent, believing that their family will never be like it was before their relative became ill, but they may also see their relative's illness as relatively permanent. Perceiving illness permanency is the core of the second domain of the family engulfment construct. Chronicity and hope are concepts highly relevant to this domain. Opinions about the ongoing need for medication, hospitalization and financial support reflect the degree to which family members perceive illness permanency. The degree to which family members perceive illness permanency is also reflected in whether or not they are able to remain hopeful for a better future for their ill relative. Viewing the illness as "chronic" or permanent is thought to contribute to the engulfment of family members. The engulfment of family members, however, may be counterbalanced by a sense of hope regarding their ill relative's future.

Domain 3: The family member's acceptance of their relative's mentally ill label.

Whether or not family members actually accept their relative's mentally ill label is also thought to contribute to family engulfment. Reflecting on family engulfment as a construct that offers a perspective for understanding how a family's identity and how a family member's self-identity may incorporate the experience of mental illness, it stands to reason that the process of family engulfment may require, or at least involve, a recognition and acceptance of the existence

of mental illness. Stigma is highly relevant to this domain. Family members may be reluctant to accept their relative's diagnosis of schizophrenia or even entertain the possibility of such a diagnosis, partly, if not completely, related to the stigma still associated with this diagnosis. As family members come to accept their relative's mentally ill label, they may come to define themselves and their family in terms of this label. On the other hand, family members who maintain that their relative is not mentally ill may be less engulfed by the illness experience.

Domain 4: A loss of normal roles for family members.

Stigma is also highly relevant to the fourth domain: a loss of normal roles for family members. Stigma often results in the social isolation of family members. This occurs in two ways: 1) extended family, friends, co-workers and acquaintances may distance themselves from individuals who have a relative with schizophrenia due to the stigma still associated with this diagnosis and 2) family members of individuals with schizophrenia may distance themselves from others in anticipation of stigma, discrimination and rejection. The social isolation of family members then results in a loss of social roles for family members. Furthermore, as family members begin feeling more comfortable and more closely aligned with other families who have mentally ill relatives than with people who have never known the experience of living with mental illness, they may reconstruct their social circles, resulting in a loss of social roles. Moreover, the self-identity of family members is likely to be impacted by a loss of social roles.

Domain 5: Negatively comparing one's family to other families.

The ability of the family to maintain the semblance of a normal life under the abnormal presence of a chronic illness is a challenge for families of individuals with schizophrenia. "Normal", however, is a relative term. Families of individuals with schizophrenia not only negatively compare themselves to the family they were before their relative became ill but they negatively compare themselves to other families as well. Families who have a member with schizophrenia see themselves as being different from other families because of their relative's illness and also perceive that others see them as being different. The notion of being "different" from other families is reflective of the loss of the "normal" pre-illness family identity as well as the stigma of mental illness.

Appendix C: Case Studies

Please read Appendix B for a description of the family engulfment construct and the domains of the Modified Engulfment Scale – Family Version (MES-FV). Following that, please read the two case studies below. For each case study, please indicate whether each of the five domains of the MES-FV is present or absent. In other words, please indicate which of the five domains of the MES-FV are clearly identifiable in each case study and which are not.

Case Study #1

Eve and her husband, Rick, have a son named Alex. Alex is 19 years old and is in his first year of university. He is attending the university in his hometown and continues to live at home with his parents. A few months ago, Eve and Rick began to notice some dramatic changes in Alex. He was always a good student but then suddenly his grades began to slip. Although he was always outgoing and had a number of close friends, he became increasingly withdrawn. Of most concern to Eve and Rick was Alex's bizarre behavior. He had become quite suspicious and concerned that people were making fun of him.

Eve and Rick eventually ended up bringing Alex to see a psychiatrist and he was diagnosed with schizophrenia. Since then, Alex has had one admission to hospital and has been started on risperidone. Eve and Rick are struggling to adjust to the changes in Alex and in their family. They are often sad and overwhelmed because of their son's illness. They are trying hard to go about their daily lives just as they always had but they often find themselves longing for the way things used to be. Although they attempt to engage Alex in family activities, they are careful to give him his space and not to push him too hard. Different doctors have told Eve and Rick that schizophrenia is a chronic illness marked by exacerbations and remissions. While they accept that Alex has schizophrenia, stories about other young people who have recovered well from a first episode of schizophrenia offer them a sense of hope. Eve and Rick are grateful that the risperidone seems to be helping Alex and look forward to a point in time when he will not need antipsychotic medication. When this time comes, Eve and Rick hope that their family will go back to normal.

Domain 3: The family member's acceptance of their relative's mentally ill label

Whether or not family members actually accept their relative's mentally ill label is also thought to contribute to family engulfment. Reflecting on family engulfment as a construct that offers a perspective for understanding how a family's identity and how a family member's self-identity may incorporate the experience of mental illness, it stands to reason that the process of family engulfment may require, or at least involve, a recognition and acceptance of the existence

Case Study #2

Dan and his wife, Marie, have three daughters. Their eldest daughter, Jane, is 31 years old and was diagnosed with schizophrenia ten years ago. Their other two daughters are Cara, age 25, and Hana, age 21. Over the past ten years, Jane has had numerous admissions to hospital. She is currently taking olanzapine and, despite some weight gain, is tolerating this medication fairly well. She currently endorses no positive symptoms but continues to experience negative symptoms.

Having lived with the illness for the past ten years, Dan and Marie are beginning to lose hope. They are beginning to wonder whether their family will ever be like it was before Jane became ill. They fear that Jane will likely always have to take antipsychotic medication because the last time she stopped taking it, she needed to be hospitalized. They also fear that Jane will probably need to be hospitalized again at some point in the future. Jane has been out of school for the past ten years with no plans to return. Even finding a part-time job seems to be difficult for her. Dan and Marie are beginning to wonder whether they might have to support Jane indefinitely.

Dan and Marie have joined a number of support groups for parents with a son or daughter with schizophrenia over the past 10 years. Slowly over time, all of their friends have come to be other parents who have mentally ill children. Their old friends just didn't seem to understand what they were going through and some even pretended that nothing was wrong. They didn't ask about Jane and how she was doing, and they certainly weren't comfortable talking about her illness. Also, it became increasingly difficult for Dan and Marie to maintain those old friendships because they always seemed to be dealing with illness-related concerns. Because of Jane's illness, Dan and Marie feel that they will always be different from other families. Given this, it's just easier for them to be friends with other parents who have children with mental illness.

9. "Once a mental patient, always a mental patient."	1	2	3	4	5
10. Once having been hospitalized for psychiatric problems, there is a stigma that they and their family members will always be different from other families.	1	2	3	4	5
11. Our relative will probably need to be hospitalized again.	1	2	3	4	5
12. We can never truly understand what it's like to be a person with a mental illness, as well as their relative's illness, as a relatively healthy person.	1	2	3	4	5
13. We are more worried and nervous than other families.	1	2	3	4	5
14. I am disappointed in my family member's acceptance of their mental illness.	1	2	3	4	5
15. My relative really does not need psychiatric care at all.	1	2	3	4	5
16. Our relative will always have to take psychiatric medicine.	1	2	3	4	5
17. My relative's illness keeps me from having close friends.	1	2	3	4	5
18. We will always be different from other families because of our relative's illness.	1	2	3	4	5
19. I am losing my mind.	1	2	3	4	5
20. I worry that other members of my family may become mentally ill.	1	2	3	4	5
21. We are damaged as a family by our relative's illness.	1	2	3	4	5
22. It is good for our relative to stay in hospital for a long time.	1	2	3	4	5

For each case study, please circle whether each of the five domains of the MES-FV is present or absent.

There are several items of the MES-FV that are reversed scored. Please keep in mind that for a domain to be present, it does not necessarily mean that the family member is engulfed. For example, the presence of the first domain: a family member's sense that they and their family have changed, may be reflected by comments about having changed or about having remained the same.

Case Study #1

Domain 1: A family member's sense that they and their family have changed

Present Absent

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent

Present Absent

Domain 3: The family member's acceptance of their relative's mentally ill label

Present Absent

Domain 4: A loss of normal roles for family members

Present Absent

Domain 5: Negatively comparing one's family to other families

Present Absent

Case Study #2

Domain 1: A family member's sense that they and their family have changed

Present Absent

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent

Present Absent

Domain 3: The family member's acceptance of their relative's mentally ill label

Present Absent

Domain 4: A loss of normal roles for family members

Present Absent

Domain 5: Negatively comparing one's family to other families

Present Absent

Appendix D: Domain and Item Matching

Please refer back to Appendix B for a description of the five MES-FV domains. Beside each MES-FV item, please circle the corresponding domain. Keep in mind that there are several items of the MES-FV that are reversed scored.

Domain 1: A family member's sense that they and their family have changed

Domain 2: Seeing this change, as well as their relative's illness, as relatively permanent

Domain 3: The family member's acceptance of their relative's mentally ill label

Domain 4: A loss of normal roles for family members

Domain 5: Negatively comparing one's family to other families

MES-FV Item	Corresponding Domain
1. Our family manages as well as most families do.	1 2 3 4 5
2. In my opinion, my relative is mentally ill.	1 2 3 4 5
3. Because of our relative's illness, we can't do the things that other families do.	1 2 3 4 5
4. Our relative is healthy in body and mind.	1 2 3 4 5
5. Our family will never be like it was before our relative became ill.	1 2 3 4 5
6. At some point in time, our relative will not need psychiatric medications.	1 2 3 4 5
7. Our friends and family see us only as a family with problems.	1 2 3 4 5
8. For our family to be really well, our family will have to go through a change.	1 2 3 4 5
9. "Once a mental patient, always a mental patient."	1 2 3 4 5
10. Once having been hospitalized for psychiatric problems, there is a good chance of it happening again.	1 2 3 4 5
11. Our relative will probably need to be hospitalized again.	1 2 3 4 5
12. We can only be friends with other families who have mentally ill relatives.	1 2 3 4 5
13. We are more worried and nervous than other families.	1 2 3 4 5
14. I am often depressed because of my relative's illness.	1 2 3 4 5
15. My relative really does not need psychiatric care at all.	1 2 3 4 5
16. Our relative will always have to take psychiatric medicine.	1 2 3 4 5
17. My relative's illness keeps me from having close friends.	1 2 3 4 5
18. We will always be different from other families because of our relative's illness.	1 2 3 4 5
19. I am afraid of losing my mind.	1 2 3 4 5
20. I worry that other members of my family may become mentally ill.	1 2 3 4 5
21. We are damaged as a family by our relative's illness.	1 2 3 4 5
22. It is good for our relative to stay in hospital for a long time.	1 2 3 4 5

MES-FV Item	Corresponding Domain				
23. I fear that my family might have to provide financial support to my relative indefinitely.	1	2	3	4	5
24. There are many things we used to be able to do as a family that we can't do now.	1	2	3	4	5
25. Right now, we are no longer the family we were before our relative became ill.	1	2	3	4	5
26. Our relative can look forward to being married or having a steady partner.	1	2	3	4	5
27. I expect my relative to be well in the future.	1	2	3	4	5
28. Our relative's mind is normal.	1	2	3	4	5
29. Our relative will be able to find work in the very near future.	1	2	3	4	5
30. We are basically the same family we were before our relative became ill.	1	2	3	4	5

Appendix E: Relevance Ratings

Please refer back to Appendix B for a description of the family engulfment construct and the domains of the MES-FV. Please rate each MES-FV item in terms of its relevance to the family engulfment construct. Please use the following scale: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant. Keep in mind that there are several items of the MES-FV that are reversed scored.

MES-FV Item	Relevance to the Family Engulfment Construct			
1. Our family manages as well as most families do.	1	2	3	4
2. In my opinion, my relative is mentally ill.	1	2	3	4
3. Because of our relative's illness, we can't do the things that other families do.	1	2	3	4
4. Our relative is healthy in body and mind.	1	2	3	4
5. Our family will never be like it was before our relative became ill.	1	2	3	4
6. At some point in time, our relative will not need psychiatric medications.	1	2	3	4
7. Our friends and family see us only as a family with problems.	1	2	3	4
8. For our family to be really well, our family will have to go through a change.	1	2	3	4
9. "Once a mental patient, always a mental patient."	1	2	3	4
10. Once having been hospitalized for psychiatric problems, there is a good chance of it happening again.	1	2	3	4
11. Our relative will probably need to be hospitalized again.	1	2	3	4
12. We can only be friends with other families who have mentally ill relatives.	1	2	3	4
13. We are more worried and nervous than other families.	1	2	3	4
14. I am often depressed because of my relative's illness.	1	2	3	4
15. My relative really does not need psychiatric care at all.	1	2	3	4
16. Our relative will always have to take psychiatric medicine.	1	2	3	4
17. My relative's illness keeps me from having close friends.	1	2	3	4
18. We will always be different from other families because of our relative's illness.	1	2	3	4
19. I am afraid of losing my mind.	1	2	3	4
20. I worry that other members of my family may become mentally ill.	1	2	3	4
21. We are damaged as a family by our relative's illness.	1	2	3	4
22. It is good for our relative to stay in hospital for a long time.	1	2	3	4
23. I fear that my family might have to provide financial support to my relative indefinitely.	1	2	3	4

MES-FV Item	Relevance to the Family Engulfment Construct			
24. There are many things we used to be able to do as a family that we can't do now.	1	2	3	4
25. Right now, we are no longer the family we were before our relative became ill.	1	2	3	4
26. Our relative can look forward to being married or having a steady partner.	1	2	3	4
27. I expect my relative to be well in the future.	1	2	3	4
28. Our relative's mind is normal.	1	2	3	4
29. Our relative will be able to find work in the very near future.	1	2	3	4
30. We are basically the same family we were before our relative became ill.	1	2	3	4

Appendix F: General Information

Please indicate whether you are a nurse, case manager or social worker:

Nurse _____ Case Manager _____ Social Worker _____

Area of practice:

Years in your specialty:

Years of experience working with families (cumulative):

Age:

Gender: Male _____ Female _____

Reference List

- Angermeyer, M.C., Schulze, B., & Dietrich, S. (2003). Courtesy stigma: A focus group study of relatives of schizophrenia patients. *Social Psychiatry and Psychiatric Epidemiology*, 38, 593-602.
- Beanlands, H.J. (2001). *Engulfment among adults with chronic renal disease: A study of self-loss and its correlates*. Unpublished Doctoral Dissertation, The University of Toronto, Toronto, Ontario, Canada.
- Beanlands, H.J., Lipton, J.H., McCay, E.A., Schimmer, A.D., Elliot, M.E., Messner, H.A. et al. (2003). Self-concept as a "BMT patient", illness intrusiveness, and engulfment in allogeneic bone marrow transplant recipients. *Journal of Psychosomatic Research*, 55, 419-425.
- Beanlands, H., McCay, E., and Landeen, J. (2006). Strategies for moving beyond the illness in early schizophrenia and in chronic kidney disease. *The Canadian Journal of Nursing Research*, 38(3), 10-30.
- Beiser, M., Waxler-Morrison, N., Iacono, W., Lin, T., Fleming, J., & Husted, J. (1987). A measure of the 'sick' label in psychiatric disorder and physical illness. *Social Science & Medicine*, 25(3), 251-261.
- Bellack, A.S. (2006). Scientific and consumer models of recovery in schizophrenia: Concordance, contrasts, and implications. *Schizophrenia Bulletin*, 32(3), 432-442.
- Brady, N., & McCain, G.C. (2004). Living with schizophrenia: A family perspective. *Online Journal of Issues in Nursing*, 10(1), 1-28. Retrieved December 20, 2006, from http://nursingworld.org/ojin/hirsh/topic4/tpc4_2.htm.

- Buizza, C., Schulze, B., Bertocchi, E., Rossi, G., Ghilardi, A., & Pioli, R. (2007). The stigma of schizophrenia from the patients' and relatives' view: A pilot study in an Italian rehabilitation residential care unit. *Clinical Practice and Epidemiology in Mental Health*, 3, 1-8.
- Burns, N. & Grove, S.K. (2005). *The practice of nursing research: Conduct, critique and utilization* (5th ed.). St. Louis: Elsevier Saunders.
- Burns, N. & Grove, S.K. (2009). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (6th ed.). St. Louis: Elsevier Saunders.
- Corrigan, P.W. & Wassel, A. (2008). Understanding and influencing the stigma of mental illness. *Journal of Psychosocial Nursing and Mental Health Services*, 46(1), 42-48.
- Czuchta, D.M., & McCay, E. (2001). Help-seeking for parents of individuals experiencing a first episode of schizophrenia. *Archives of Psychiatric Nursing*, 15(4), 159-170.
- Davis, L.L. (1992). Instrument review: Getting the most from your panel of experts. *Applied Nursing Research*, 5, 194-197.
- Estroff, S.E. (1989). Self, identity, and subjective experiences of schizophrenia: In search of the subject. *Schizophrenia Bulletin*, 15(2), 189-196.
- Ferriter, M., & Huband, N. (2003). Experiences of parents with a son or daughter suffering from schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, 10, 552-560.
- Gonzalez-Torres, M.A., Oraa, R., Aristegui, M. Fernandez-Rivas, A. & Guimon, J. (2007). Stigma and discrimination towards people with schizophrenia and their family members. *Social Psychiatry and Psychiatric Epidemiology*, 42, 14-23.
- Harrison, G., Hooper, K., Craig, T., et al. (2001). Recovery from psychotic illness: A 15 and 25 year international follow-up study. *British Journal of Psychiatry*, 178, 506-517.

- Harrow, M., Grossman, L., Jobe, T.H., & Herbener, E.S. (2005). Do patients with schizophrenia ever show periods of recovery? A 15 year multi-follow-up study. *Schizophrenia Bulletin*, 31, 723-734.
- Johnson, M.J. & Rogers, S. (2006). Development of the purposeful action medication-taking questionnaire. *Western Journal of Nursing Research*, 28(3), 335-351.
- Karp, D.A. & Tanarugsachock, V. (2000). Mental illness, caregiving, and emotion management. *Qualitative Health Research*, 10(1), 6-25.
- Kelly, M. & Gamble, C. (2005). Exploring the concept of recovery in schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, 12, 245-251.
- Koukia, E., & Madianos, M.G. (2005). Is psychosocial rehabilitation of schizophrenic patients preventing family burden? A comparative study. *Journal of Psychiatric and Mental Health Nursing*, 12, 415-422.
- Lally, S.J. (1989). "Does being in here mean there is something wrong with me?" *Schizophrenia Bulletin*, 15(2), 253-265.
- Lemert, E.M. (1951). *Social pathology*. New York: MacGraw Hill.
- Lemert, E.M. (1967). *Human deviance, social problems, and social control*. Englewood Cliffs, NJ: Prentice-Hall.
- Liberman, R.P., Kopelowicz, A., Ventura, J., & Gutkind, D. (2002). Operational criteria and factors related to recovery from schizophrenia. *International Review of Psychiatry*, 14, 256-272.
- Link, B.G., Mirotnik, J., & Cullen, F.T. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior*, 32, 302-320.

- Lynn, M.R. (1986). Determination and quantification of content validity. *Nursing Research*, 35, 382-385.
- Magliano, L., Fiorillo, A., De Rosa, C., Malangone, C., & Maj, M. (2005). Family burden in long-term diseases: A comparative study in schizophrenia vs. physical disorders. *Social Science & Medicine*, 61, 313-322.
- McCay, E.A. (1994). *A study to assess the construct validity of the Modified Engulfment Scale*. Unpublished Doctoral Dissertation, The University of Toronto, Toronto, Ontario, Canada.
- McCay, E., Beanlands, H., Leszcz, M., Goering, P., Seeman, M.V., Ryan, K., et al. (2006). A group intervention to promote healthy self-concepts and guide recovery in first episode schizophrenia: A pilot study. *Psychiatric Rehabilitation Journal*, 30(2), 105-111
- McCay, E., Beanlands, H., Zipursky, R., Roy, P., Leszcz, M., Landeen, J., et al. (2007). randomized controlled trial of a group intervention to reduce engulfment and self-stigmatization in first episode schizophrenia. *Australian e-Journal for the Advancement of Mental Health*, 6(3), 1-9.
- McCay, E., Ryan, K., & Amey, S. (1996). Mitigating engulfment: Recovering from a first episode of psychosis. *Journal of Psychosocial Nursing*, 34(11), 40-44.
- McCay, E.A., & Seeman, M.V. (1998). A scale to measure the impact of a schizophrenic illness on an individual's self-concept. *Archives of Psychiatric Nursing*, 12(1), 41-49.
- Milliken, P.J., & Northcott, H.C. (2003). Redefining parental identity: Caregiving and schizophrenia. *Qualitative Health Research*, 13(1), 100-113.
- Munro, B.H. (2001). *Statistical methods for health care research* (3rd ed.). Philadelphia: Lippincott.

- Nunnally, J.C., & Bernstein, I.H. (1994). *Psychometric theory* (3rd ed.). New York: McGraw-Hill.
- Onken, S.J., Craig, C.M., Ridgway, P., Ralph, R.O., & Cook, J.A. (2007). An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal*, 31(1), 9-22.
- Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: Parents' narratives. *Health and Social Care in the Community*, 9(4), 194-204.
- Phelan, J.C., Bromet, E.J., & Link, B.G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24(1), 115-126.
- Polit, D.F., & Beck, C.T. (2006). The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health*, 29, 489-497.
- Polit, D.F., Beck, C.T., & Owen, S.V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, 30, 459-467.
- Rolland, J.S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process*, 26, 203-221.
- Romano, D.M. (2009). *Reshaping an enduring sense of self: The process of recovery from a first episode of schizophrenia*. Unpublished Doctoral Dissertation, The University of Toronto, Toronto, Ontario, Canada.
- Rosenberg, M. (1979). *Conceiving the self*. New York: Basic Books.
- Rudge, T., & Morse, K. (2004). Did anything change? Caregivers and schizophrenia after medication changes. *Journal of Psychiatric and Mental Health Nursing*, 11, 3-11.

- Schulze, B., & Angermeyer, M.C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine*, 56, 299-312.
- Schur, E.M. (1971). *Labeling deviant behavior: Its sociological implications*. New York: Harper & Row.
- Skaff, M.M., & Pearlin, L.I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist*, 32, 656-664.
- Tsang, H., Tam, P., Chan, F., & Chang, W. (2003). Sources of burdens on families of individuals with mental illness. *International Journal of Rehabilitation Research*, 26(2), 123-130.
- Tuck, I., Du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, 11(3), 118-125.