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# The Effect of a Culturally-Informed Therapy for Schizophrenia on Caregiver Burden, Perceptions of Interdependence and Self-Conscious Emotions

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UNIVERSITY OF MIAMI

THE EFFECT OF A CULTURALLY-INFORMED THERAPY FOR  
SCHIZOPHRENIA ON CAREGIVER BURDEN, PERCEPTIONS OF  
INTERDEPENDENCE AND SELF-CONSCIOUS EMOTIONS

By

Giulia Caitlin Suro

A DISSERTATION

Submitted to the Faculty  
of the University of Miami  
in partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

Coral Gables, Florida

August 2014

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The Effect of a Culturally-Informed Therapy  
For Schizophrenia on Caregiver Burden, Perceptions  
Of Interdependence and Self-Conscious Emotions.

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Abstract of a dissertation at the University of Miami.

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Research has demonstrated that taking care of a patient with schizophrenia has serious mental health costs to caregivers that include high levels of burden and poorer overall mental health. Thus, it is necessary to pinpoint predictors of caregiver distress and develop strategies to reduce it. We have developed a family focused, culturally-informed treatment for schizophrenia (CIT-S). We examined this intervention and its ability to decrease the maladaptive behaviors, beliefs, and values that we believe contribute to caregiver distress. CIT-S was compared against a three-session psychoeducation condition in a sample of 113 caregivers of patients with schizophrenia. Specifically, we hypothesized that schizophrenia caregivers who completed CIT-S would demonstrate lower levels of caregiver burden, shame and guilt/self-blame, as well as increased perceived interdependence when compared to participants who completed psychoeducation. Additionally, we hypothesized that shame, guilt/self-blame and interdependence would mediate the relationship expected between treatment type and caregiver burden. In line with hypotheses, CIT-S was found to decrease caregivers' burden and guilt/self-blame when compared to the psychoeducation condition. Also consistent with hypotheses, reductions in guilt/self-blame were found to mediate the changes in caregiver burden associated with treatment type. Treatment type did not

appear to influence shame nor interdependence. Study implications are discussed and a case vignette is provided.

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## Chapter 1: Introduction

### *Study Overview*

Schizophrenia is a disabling, chronic psychiatric disorder that occurs in approximately 1% of the population (Goldner, Hsu, Waraich & Somers, 2002; Mueser & Jeste, 2008). It has severe consequences for patients with the disorder, as well as their caregivers who often present with high levels of psychological distress (Awad & Voruganti, 2008). Research indicates that the relationship between a patient and their family environment is complex and characterized by dynamic processes that have implications for the patient's course of illness (e.g. Hooley & Gotlib, 2000). Additionally, recent work suggests that certain caregiver values and emotions may influence caregiver burden and psychological distress. The current standard treatment available for families of patients with schizophrenia is family psychoeducation (McFarlane, Dixon, Lukens & Lucksted, 2003). Psychoeducation has demonstrated efficacy in improving patient prognosis and severity (Jewell, Downing & McFarlane, 2009; Murray-Swank & Dixon, 2004; Rummel-Kluge & Kissling, 2008). However, research indicates that this population continues to experience a great deal of burden (McDonell, Thorson & Disher, 2003). Prior studies suggest that interdependence, shame and guilt/self-blame are three constructs that may influence caregiver burden and should therefore be examined in a treatment setting (Suro & Weisman de Mamani, 2012; Wasserman, Weisman de Mamani & Suro, 2012). We have developed a 15 week, family-focused, culturally-informed intervention with the intention of decreasing levels of caregiver burden, shame and guilt/self-blame, and increasing levels of interdependence. This treatment is considered to be "culturally informed" because it accesses beliefs, behaviors and practices from clients'

cultural backgrounds that may be adaptive or, in some cases, maladaptive in coping with schizophrenia. Adaptive beliefs and behaviors are encouraged throughout treatment while attempts are made to modify maladaptive ones. The treatment also strongly aims to foster collective beliefs and values as well as spiritual practices that research suggests are culturally-sanctioned for minorities and possibly effective for all. We compare CIT-S against a 3 session, psychoeducation only control condition. Both CIT-S and psychoeducation are described in more detail in the methods section.

### *Consequences of caregiving*

Schizophrenia poses multiple challenges in its management and consequences for both patients with the illness as well as their caregivers. In the past fifty years, the de-institutionalization of psychiatric care has resulted in many patients residing at home. It is estimated that from 50 to 90% of American adults with schizophrenia live with a relative (Awad & Voruganti, 2008; Talbott, 1990; WHO, 2001). Consequently, family members are now increasingly responsible for providing basic caregiving services to their mentally ill loved ones and may find themselves in a role for which they have little preparation or training. Typical stressors associated with caring for a patient with schizophrenia often include addressing patients' unpredictable, intrusive, and/or potentially inappropriate behaviors, as well as frustration due to lack of patient motivation, poor grooming and difficulty displaying affect (Hatfield, 1978). Not surprisingly, the transition to caregiving has been associated with numerous negative outcomes including impaired personal, social and vocational role performance (Gallagher & Mechanic, 1996; Jungbaur, Wittmund & Dietrich, 2003; Madianos, Economou & Dafni, 2004; Magana, Ramirez & Hernandez, 2007). Additional consequences include increased rates of substance use

(Pruncho & Resch, 1989) and poor effects on the immune system that are associated with increased medical visits (Kiecolt-Glaser et al., 1991; Kiecolt-Glaser & Glaser, 1994). Financial constraints and other economic consequences such as decreased potential for earning and loss of productivity have also been frequently reported for schizophrenia caregivers (Knapp et al., 2004; Wu et al., 2005).

Research has demonstrated that the experience of caregiving is associated with numerous maladaptive mental health consequences as well. The most extensively investigated of these outcomes is depression. The prevalence of depression for caregivers of individuals with psychiatric illnesses has been estimated to range from 38 to 70 percent (Moller et al., 2009). Other common consequences include feelings of uncertainty and anger, as well as increased rates of self-conscious emotions such as shame and guilt/self-blame (Awad & Voruganti, 2008; Guttierrez-Maldonado, 2006; Weisman de Mamani, 2010; Wasserman et al., 2012). Research suggests that caregivers often feel stigmatized and socially isolated because of the psychiatric illness of their relative (Wahl & Harman, 1989). The many strains on caregivers have been found to contribute to an overall compromised quality of life (Gallagher & Mechanic, 1996; Noh & Turner, 1987). Finally, the experience of schizophrenia caregiving has been associated with decreased levels of confidence and perceived self-efficacy (Awad & Wallace, 1999).

The study of caregiver health and the factors that underlie the poor psychological outcomes observed for caregivers may have implications for patients with schizophrenia as well. Research in the area of expressed emotion (EE) provides support for the study of the role of a patient's family environment, in addition to the biological origins of the illness, when examining the course of schizophrenia and its prognosis. EE refers to a

measure of the family environment that is based on how the relatives of a psychiatric patient spontaneously talk about the patient (Hooley, 2007). Relatives who are high in EE have been found to speak about their loved one in an extremely critical or emotionally over-involved manner, compared to low EE relatives (e.g. Miklowitz, Goldstein, Falloon, & Doane, 1984; Strachan, Leff, Goldstein, Doane, & Burt, 1986). Extensive research has demonstrated that that high EE communication is associated with increased severity of symptoms, number of relapses and hospitalizations (e.g. Hooley, 2007; Miklowitz et al., 1984; Wearden, Tarriner, Barrowclough, Zastowny & Rahill, 2000). Additional research indicates that a caregiver's personal understanding and interpretation of their relative's illness may contribute to this maladaptive communication and its consequences for patients (Hall & Docherty, 2000; Hooley, 2007; Van Humbeck, Van Audenhove, Pieters & De Hert, 2002). Therefore, addressing caregivers' subjective experience of caretaking and illness-related stressors may target these maladaptive modes of communication and indirectly benefit patients.

### *Caregiver Burden*

The experience of caring for a patient and the psychological state that ensues is known as caregiver burden. Hoening and Hamilton (1967) conceptualized burden in terms of two distinct dimensions, objective and subjective. Objective burden (OB) is defined as stress stemming from the visible, concrete costs to a caregiver that are the direct result of the mental illness of their family member (e.g, physical and economic consequences). Subjective burden (SB) is defined as the caregiver's appraisals of these costs and the extent to which they perceive their situation to be burdensome (e.g., embarrassment, resentment). The relationship between OB, SB and mental health

outcomes has been explained by the stress-appraisal-coping theory of Lazarus and Folkman (1984). According to this theory, the symptoms and behaviors associated with a patient's illness are considered to be objective stressors that may result in strain or distress for the caregiver. However, the extent to which these stressors are related to negative mental health outcomes is dependent on the caregiver's appraisal, or subjective evaluation, of the stressor. Suro and Weisman de Mamani (2012) tested Lazarus and Folkman's (1984) conceptualization of the relationship between OB, SB and mental health outcomes in a sample of schizophrenia caregivers. Results indicated that SB partially mediated the relationship between OB and mental health outcomes demonstrating the underlying influence of the appraisal process on psychological well-being. This finding is in line with a stress-appraisal-coping model of mental health outcomes, and suggests that the objective stressors associated with caregiving may incite an appraisal process for schizophrenia caregivers. The stressors are then deemed to be either benign or distressing. This finding demonstrates the potential to improve the negative psychological outcomes associated with caregiving by addressing caregivers' subjective experience. From a clinical perspective this is positive, as an individual's appraisals may be more malleable to treatment (e.g. Bibou-Nakou, Dikaiou & Bairactaris, 1997; Rose, Bisson & Wessley, 2002), while objective stressors are much more constrained. Therefore, further research is needed to examine the specific values and emotions that may influence caregivers' subjective experience of caregiving and subsequent levels of burden and psychological distress.

### *Interdependence*

Interdependence is a construct that research suggests has implications for caregivers and thus may be a worthy value to target in treatment. Interdependence, or the interconnectedness of individuals within a group, entails viewing oneself as part of an all-encompassing social group, and consequently guiding one's behavior based on the feelings, actions, or standards established by the larger whole (Markus & Kitayama, 1991). Singelis (1994) posits that interdependence is a perception of self that emphasizes relationships with others, fitting in, occupying one's "proper place" and engaging in the appropriate actions for a given situation. Research suggests that endorsing the value of interdependence may promote a positive caregiving experience and consequently may have implications for the mental well-being of both caregivers and patients with a severe mental illness. In a study examining the relationship between interdependence and objective and subjective burden in a sample of schizophrenia caregivers, Suro and Weisman de Mamani (2012) found that interdependence was a significant moderator of the objective-subjective burden relationship. That is, when levels of interdependence were high, objective burden had less of an impact on subjective burden for schizophrenia caregivers. This demonstrates that the value of interdependence may play a protective role against the detrimental effects of objective burden. These findings indicate that having a sense of oneself as connected with a larger community may serve to alleviate the stressor-appraisal process and provide a resource to caregivers who are managing the burdens frequently associated with caring for a mentally ill individual. In short, a strong perception of being interdependent with a larger community may serve to mitigate the

stressor-appraisal process and provide a resource to caregivers managing a frequently distressing situation.

Additional evidence for the influence of interdependence on caregiving attitudes can be found in ethnic differences in caregiving outcomes. The value of interdependence appears to be more inherent in certain ethnic groups. Specifically, interdependence does not appear to be as strongly endorsed by European-Americans. In fact, in many Western societies, there is a strong emphasis on remaining autonomous and deriving one's sense of self-esteem from achievements that result from internal attributes, such as one's personality traits, abilities, and intelligence (Matsumoto et al., 1997). Research indicates that Caucasians also experience more negative outcomes related to caregiving including depression (e.g. Skarupski, McCann, Bienias & Evans, 2009), global role strain (Farran & Miller, 2007), and decreased well-being and physical health (Haley, Gitlin, Wisniewski & Mahoney, 2004). Furthermore, there is a strong body of work demonstrating that African-American and Hispanic caregivers appraise the act of caregiving as more normative and less burdensome than do Caucasian caregivers and, consequently, exhibit lower levels of poor mental health as a result of caregiving (e.g. Haley, Roth & Coleton, 1996; Lawton, Rajagopal, Brody, & Kleban, 1992; Magaña et al., 2007). Perhaps one reason for the ethnic differences in psychological outcomes observed for Caucasians is the absence of a given expectation or standard establishing caring for one's family as the norm.

Although we do not examine EE directly in the current study, research from the EE literature suggests that schizophrenia caregivers who focus on maintaining group harmony and endorse more interdependent values also tend to cope more effectively with

objective stress. Base rates of high EE have been found to vary across cultures with significantly greater frequencies of high-EE found in European-American families, when compared to Hispanic families (Karno et al., 1987). Research has demonstrated that individuals who are more likely to endorse higher levels of interdependence are less conflictual and more eager to maintain group cohesion (Oetzel, 1998; Kim, Aune, Hunter, Kim & Kim, 2001). These findings suggest that a strong orientation toward interdependence may lead caregivers to have greater empathy for relatives with schizophrenia and to possibly perceive them to be less responsible for their condition as a way to preserve the solidarity of the group. This body of work demonstrates that promoting a sense of interdependence in treatment may lead to positive outcomes for schizophrenia caregivers and have indirect benefits for patients.

#### *Self-Conscious Emotions*

The self-conscious emotions of shame and guilt/self-blame have been found to have a direct impact on caregiving outcomes, and subsequently an indirect outcome on patient health (Teschinsky, 2000; Wasserman et al. 2012). However, the specific mechanisms by which this occurs are still unclear. Both of these emotions have been found to be common for caregivers of patients with schizophrenia (Awad & Voruganti, 2008). Historically, parents have carried the responsibility for the onset of their offspring's schizophrenia (Jones, Kugler & Adams, 1995). This misconception has contributed to increased experiences of guilt/self-blame, shame, as well as avoidance of treatment (Winefield & Burnett, 1996). Much more is known about the origin and onset of schizophrenia today, yet the prevalence of these emotions is still elevated for parents of patients with schizophrenia (Teschinsky, 2000). The emotions of shame and guilt/self-

blame share a number of similarities. Both are self-evaluative emotions. That is, they lead individuals to reflect on their self-representations and to contemplate how an emotion-eliciting event is relative to these representations (Tracy & Robins, 2006). Additionally, as individuals often experience shame and guilt/self-blame within the context of important interpersonal relationships, these emotions have implications for interpersonal functioning (Tangney, 1995).

While the two terms, shame and guilt/self-blame, have been used interchangeably in the past (Tomkins, 1963), research has demonstrated that shame and guilt/self-blame may serve distinct functions and on occasion may lead to different outcomes. When an individual experiences shame, the self is typically the object of negative self-evaluation, and one often regulates this negative experience by externalizing blame onto others (Tracy & Robins, 2006). Consequently, shame has been found to be associated with more psychological distress than guilt/self-blame (Tangney, 1995). While humiliation and disgrace may describe the subjective experience of feeling shame, guilt/self-blame, on the other hand, may be characterized by repentance and blameworthiness (Mosher & White, 1981). When individuals experience guilt/self-blame, one's behaviors are often the object of negative self-evaluation, thus they may be more likely to take ownership for a negative event (Tangney, 1995). As a result, guilt/self-blame is sometimes associated with pro-social and reparative behaviors, while shame is related to behaviors such as hiding and social withdrawal (Tangney & Dearing, 2002).

Despite some work demonstrating distinctions in experience and outcome, research has demonstrated that there are few antecedent events that specifically elicit either shame or guilt/self-blame (Keltner & Buswell, 1996). Theorists posit that it is not

the antecedent events, per se, that lead to the experience of a specific emotion, but rather how the events are appraised by the individual (e.g. Lazarus, 1991; Tracy & Robbins, 2006). Tracy and Robbins (2004) have proposed an appraisal-based model of self-conscious emotions in which experiences such as shame, guilt/self-blame, pride and embarrassment are elicited by an individual's appraisals about an event's implications for one's identity. According to this model, individuals will experience guilt/self-blame when they attribute an outcome to a negative aspect of their *behavior* (e.g. hurting someone's feelings, stealing something that did not belong to them). Shame on the other hand occurs when one focuses on a negative aspect of *themselves* (e.g. being a cruel person, being a dishonest person) (Lewis, 1971, p. 30; Lewis, 2000; Tangney & Dearing, 2002). Additionally, guilt/self-blame has been found to occur when one attributes the eliciting event to unstable aspects of one's self, while shame results when one blames the stable self (Tracy & Robbins, 2006). For example, guilt/self-blame related to poor performance on a test may be explained by "I didn't study hard enough for this exam," while feelings of shame may be attributed to an explanation such as "I'm not smart." Both of these emotions are self-conscious and are elicited by internal attributions, however the emotions will differ based on the attribution or explanation employed by the individual. As previous research has demonstrated, appraisals related to the burden of caregiving may play more of a key role in subsequent psychological outcomes than the concrete stressors that exist in a caregiver's life (Suro & Weisman de Mamani, 2012). This suggests that interventions targeting the appraisal processes underlying caregivers' shame and guilt/self-blame may reduce subsequent levels of caregiver burden.

As mentioned, prior work has demonstrated that self-conscious emotions have direct consequences for caregiver well-being and consequently indirect implications for patient health. Specifically, both shame and guilt/self-blame have been found to be associated with the way an individual responds to challenges or adversity (Conradt, Dierk, Schlumberger, Rauh & Hebebrand, 2008; Jenkins & Karno, 1992). Feelings of shame have been associated with coping responses of a critical, hostile nature that are more likely to correspond with high EE communication and behaviors. Ryan (1993) found nonverbal evidence of feelings of shame in high EE responses from relatives of patients with schizophrenia and concluded that relatives' criticism might be a consequence of shame. Recently, Wasserman and colleagues (2012) found that higher levels of both shame and guilt/self-blame about having a relative with schizophrenia predicted high EE. Building upon these findings, further research is needed to examine the role that self-conscious emotions may play in the poor psychological outcomes common among schizophrenia caregivers. Understanding the link between self-conscious emotions and caregiver outcomes may have implications for patients and family members alike.

Despite the clear implications of shame and guilt/self-blame for interpersonal functioning and mental health, there is little research on the role of self-conscious emotions in caregivers (Pulakos, 1996). Pulakos posits that the experience of shame and guilt/self-blame among caregivers may lead to unique family profiles. For instance, shame in a family member may lead to expressions of rage or hostility toward other family members and thus more family conflict (Scheff, 1995). Previous research in the area of guilt/self-blame indicates that this emotion may motivate a tendency to engage

with others to repair wrongdoings (Wasserman et al., 2012). Relatives who feel that they are to blame for having a loved one with schizophrenia may seek more contact with the patient in order to mend the offenses they believe they have inflicted on the patient.

These limited findings indicate that additional research is needed to clarify the roles of shame and guilt/self-blame within familial relationships, and specifically for families coping with schizophrenia.

### *Family Interventions for Schizophrenia*

The research described above demonstrates the complex and fragile dynamics that exist between patients with schizophrenia and their caregivers. Therefore, ongoing investigation and evaluation of interventions specifically tailored for these families is critical. Antipsychotic medications have repeatedly shown to be an effective first-line treatment for patients with schizophrenia in the prevention of relapse. However, with the emergence of the EE literature and findings demonstrating the impact of family environment on patient prognosis, researchers have recognized the importance of developing interventions for patients with schizophrenia and their families. Additionally, work in the area of medication compliance indicates that the social context in which pharmacological treatment is delivered may have a major impact on its success, further demonstrating the need to incorporate family into treatment (Bebbington & Kuipers, 1994). In 1998, the Robert Wood Johnson Foundation convened a consensus panel of clinicians and administrators from the National Alliance for the Mentally Ill (NAMI) to identify six areas of practice for patients with schizophrenia that have empirical support in the literature. A primary recommendation was the incorporation of family members into psychosocial treatment with the patient. This guideline is also in line with the

Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations developed from an extensive review of the treatment literature (Lehman & Steinwachs, 1998). The first recommendation that emerged from the PORT research posits that if patients have ongoing contact with family members they should engage in a family psychoeducation intervention that offers education about the illness, family support and training in problem-solving skills and crisis prevention.

Subsequent research supports the inclusion of relatives in treatment for patients with schizophrenia. A meta-analysis conducted by Pitschel-Walz and colleagues (2001) demonstrates that relapse rates for patients with schizophrenia may be dramatically reduced if the patient's relatives are incorporated into treatment. Similar research indicates that living with supportive relatives increases medication adherence for patients with schizophrenia (Fenton et al., 1997; Frauenglass et al., 1997). Additional findings have demonstrated that incorporating family into treatment is beneficial for caregivers. Participating in treatment with one's relative diagnosed with schizophrenia has been associated with improved caregiver physical well-being (e.g. McFarlane et al., 2003; Shi, Zhao, Xu & Sen, 2000; Solomon, Draine, Mannion & Meisel, 1996), increased use of active coping skills (Shean, 2009) and decreased disruption in daily activities (Falloon & Pederson, 1985).

Despite these findings and recommendations, most mental health facilities still lack family treatments of any type (Lefley, 2002). In a nation-wide study examining data from Medicare and Medicaid claims for patients with schizophrenia, Dixon and colleagues (1999) found that less than 7% of patients had a paid outpatient claim for family therapy. Additionally, a survey of psychiatric staff in mental health settings

demonstrated numerous perceived obstacles to implementing family programs including a paucity of programmatic leadership in implementation, insufficient resources and a lack of access to training opportunities (Dixon, Adams & Lucksted, 2000). Data pertaining to the dissemination of family programs outside of medical settings are widely unknown. These findings underscore the need to develop and evaluate psychosocial interventions for patients with schizophrenia and their families.

Family psychoeducation is one evidence-based intervention that has been offered to patients with schizophrenia and their family members with increasing sophistication for over twenty years (McFarlane et al., 2003). It is currently the most researched and highly disseminated intervention for patients with schizophrenia that incorporates family members (Dixon et al., 2000; Drake, Mueser, Torrey, Miller & Lehman, 2000). Family psychoeducation as an intervention originated from multiple sources, therefore the specific components of psychoeducation programs may differ from setting to setting (McFarlane et al., 2003). However, successful programs have been found to share several common characteristics: 1) they regard schizophrenia as a biological illness, 2) they enlist family members as therapeutic agents and 3) they offer varying combinations of education about mental illness, practical and emotional support, and skill development in relapse prevention and crisis management (Dixon et al., 2000). Family psychoeducation programs may be conducted with individual families or multifamily groups, and may vary in length and timing with regard to the patient's stage in the illness. However, research indicates that when it is implemented, family psychoeducation most commonly consists of brief (1-3 sessions) education oriented programs (Lucksted, McFarlane, Downing, Dixon & Adams, 2012).

Over twenty clinical trials have found that psychoeducation interventions for families reduce the risk of relapse for patients with schizophrenia (Dixon et al., 2000; Lehman & Steinwachs, 1998; Miklowitz & Goldstein, 1997; Pharoah, Mari, Rathbone & Wong, 2004). Additionally, considerable evidence has demonstrated that family psychoeducation is a solid evidence-based effective practice for reducing both positive and negative symptoms, the number and duration of hospitalizations, as well as increasing medication adherence and improving social functioning for patients with schizophrenia (Dyck, Short, Voss, Hendryx & Hanken, 2002; Kopelowicz, Zarate, Wallace, Liberman, Lopez & Mintz, 2012; Magliano, Fiorillo, Nakabgiben, 2006; Murray-Swank & Dixon, 2004; Rummel-Kluge & Kissling, 2008). Family psychoeducation interventions have been shown to have benefits for schizophrenia caregivers as well. In a meta-analysis reviewing 16 controlled trials, Cuijpers (1999) found that, as a class of interventions, family psychoeducation has demonstrated efficacy in reducing negative attitudes towards the patient. Additionally, these programs have led to improvements in family functioning and family member levels of general satisfaction (Smith & Birchwood, 1996). Similarly, Xiong and colleagues (1994) found that family psychoeducation was effective in reducing reported family conflict and disruption. Trials of family psychoeducation have also demonstrated this intervention's efficacy in improving family member well-being (Cuijpers, 1999; Shi et al., 2000), decreased medical illnesses and medical care utilization (Dyck et al., 2002) and reduced impact on the costs of caring for the patient (McFarlane et al., 2003). One trial demonstrated a significant decrease in caregiver burden (e.g. Mannion et al., 1994). However, others did not display a significant effect for burden (e.g. Dyck et al., 2002; Mueser et al., 2001).

Little is known about the impact of family psychoeducation on self-conscious emotions or perceived interdependence for schizophrenia caregivers.

### *The Current Study*

These findings indicate that further investigation of schizophrenia caregivers' response to family interventions is necessary. Specifically, there is a need to identify the unique caregiver variables that underlie these observed outcomes following treatment. Given the promise demonstrated by family psychoeducation for improving caregiver well-being, it is critical to explore the constructs driving these benefits and their amenability to treatment. Understanding what causes caregivers to respond positively to treatment will lead to the refinement of current interventions like family psychoeducation. This is particularly important as little is known about the impact of family interventions on self-conscious emotions or perceived interdependence for schizophrenia caregivers, despite their demonstrated role in EE and caregiver distress. Based on what is known regarding the relationship between caregiver factors and family environment, and the influence these constructs may have on patient health, it is imperative to continue to investigate interventions that target this population.

In summary, schizophrenia is a severe and chronic mental illness that has major consequences for patients with the disorder. Additionally, it is clear that this illness has a dramatic impact on family members as well, as research demonstrates that caregivers experience high levels of burden and psychological distress. Interdependent values appear to have the potential to mitigate some of the negative outcomes associated with caregiving. Therefore, interventions that foster a sense of unity and cohesion among family members may serve to reduce caregiver distress. The self-evaluative emotions of

shame and guilt/self-blame appear to have consequences for the well-being of caregivers and patients alike. Research suggests that these emotions may be the result of a subjective appraisal process and therefore malleable to treatment. Family interventions, such as family psychoeducation, appear to be beneficial for patients with schizophrenia as well as their caregivers. However, despite these promising findings, little is known about the influence of these interventions on constructs such as interdependence, shame and guilt/self-blame. The current study tested the ability of a family-focused, culturally-informed intervention (CIT-S) for patients with schizophrenia and their families to influence caregiver well-being on a number of variables when compared to a psychoeducation condition. Specific aims of this treatment were to reduce levels of burden, shame, and guilt/self-blame, and to increase perceptions of interdependence for caregivers of patients diagnosed with schizophrenia. An additional objective was to examine whether changes in caregivers' self-conscious emotions and perceptions of interdependence accounted for the decreased levels of caregiver burden expected for participants who completed CIT-S relative to those who completed three sessions of psychoeducation.

Based on the research reviewed above, the following two sets of hypotheses were tested.

1) First, we evaluated the ability of CIT-S to influence several outcomes for caregivers of patients with schizophrenia. Specifically, it was expected that caregivers who received CIT-S would demonstrate decreased levels of a) burden, b) shame and c) guilt/self-blame, and d) increased perceptions of interdependence when compared to those who received psychoeducation only.

2) The second set of hypotheses addressed potential mediators of the relationship between treatment type and caregiver burden. It was hypothesized that changes in levels of self-conscious emotions and interdependence would partially mediate the relationship expected between treatment type and caregiver burden. Specifically, decreased levels of self-conscious emotions and increased levels of interdependence were expected to account for the reductions of caregiver burden predicted for participants who completed CIT-S, relative to those who completed psychoeducation only.

## Chapter 2: Method

### *Sample*

The sample of the current study consisted of caregivers of patients diagnosed with schizophrenia or schizoaffective disorder. In order to be eligible, caregivers had to be in regular contact with a patient diagnosed with schizophrenia or schizoaffective disorder, as confirmed by The Structured Clinical Interview for the DSM-IV, patient edition, (SCID-I/P, First, Spitzer, Gibbon, & Williams, 2002). Specifically, minimal contact of 1 or more hour per week, on average, over the past three months was required. A family member was defined as a biological relative, a step-relative, a spouse, or a significant other (SO), as long as the relationship with the SO had been in existence for at least six months and the patient described the relationship as meaningful and committed. Participants were required to give informed consent and agree to participate in all assessment and intervention phases of the study. In order to enroll, participants had to be proficient in either English or Spanish and willing to be randomly assigned to either treatment condition. For ethical reasons and to simulate real world settings, all other types of individual psychosocial treatments were permitted.

The current family member sample included 113 participants (71 female, 42 male) with a mean age of 53.77 years ( $SD = 14.93$ ), comprising 66 families. The average number of caregivers per family was 1.72. Sixty-four of these participants were randomized to and completed CIT-S, 49 caregivers were randomized to and completed psychoeducation. Seventy-one of these participants were identified as the member of the family who spends the most time with the patient. Sixty percent of the family member sample identified as Hispanic, 28.2% as Caucasian, 8% as African American and and

3.8% identified as “Other.” Seventy-two percent of the assessments took place in English, 28% were conducted in Spanish. Thirty-eight percent identified as mother of the patient, 21.8% identified as father of the patient, 7.9% identified as significant other of the patient, 10.7% identified as sister of the patient, 9.3% identified as brother of the patient, 2.3% as daughter of the patient, 1% as son of the patient, 2.5% as aunt of the patient, 3.2% as grandmother of the patient, 2.3% as cousin of the patient and 1% as step-father of the patient. Table 1 presents descriptive information for all categorical demographic data.

### *Procedure*

Participants were recruited through referrals from hospitals and community mental health centers such as Jackson Memorial Medical Center, Fellowship House, Citrus Mental Health, and Camillus House as well as in newspaper advertisements and advertisements on Miami’s above-ground rail system. Advertisements included the following questions and information:

“Have you or one of your relatives been diagnosed with schizophrenia or schizoaffective disorder? If so, you may be eligible to participate in a research study. During the study you will take part in an interview (regarding symptoms, how you cope with the illness, and cultural information) and, if interested, you may also be eligible for free family therapy for schizophrenia/schizoaffective disorder. Interviews are available in English and Spanish. You will be compensated \$25 for your interview time.”

Participants were given contact information. When participants initiated contact they first received a brief screening instrument over the phone to assess eligibility. If participants expressed interest and appeared to meet criteria they were contacted for an

initial screening assessment. During this assessment, a trained bilingual research assistant fully explained the study process, including the randomization design. The participant was asked to review study procedures, and if in agreement, to sign an informed consent form. The research assistant then interviewed the patient using the SCID-I/P to confirm diagnosis. This interview lasted approximately 1 to 1.5 hours. If the patient met study criteria, the patient and caregiver continued with a baseline assessment. This assessment lasted approximately 2 to 2.5 hours and gathered data across a variety of domains including, but not limited to, cultural identity, family dynamics, and coping strategies. Data from the assessment materials was collected in interview format. That is, interviewers read the questions and participants provided their responses orally. This procedure was chosen to address concerns regarding variability in participants' level of reading comprehension. The first family assessment occurred approximately 1-2 weeks before treatment. Participants were then randomly assigned to either fifteen weeks of CIT-S or three sessions of psychoeducation. Participants in the CIT-S condition were re-assessed using the same measures after the 15th and final session. Participants in the psychoeducation condition also received the same assessments at the same time intervals as the experimental group (i.e. fifteen weeks after the first treatment session).

#### *A Family-Focused, Culturally-Informed Therapy for Schizophrenia*

Weisman de Mamani and colleagues (2006) have developed a culturally-informed therapy for schizophrenia (CIT-S) to address the limitations of existing family interventions for this population. The majority of interventions designed for schizophrenia families are offered only in English (e.g., Miranda et al., 2005; U.S. Department of Health and Human Services, 2001) and do not take into account factors

that may be important for different cultural groups. As a result, these programs may be less relevant for ethnic/racial minority groups, who overwhelmingly report turning to spiritual and collectivistic values when coping with mental illness (Magaña et al., 2007). Additionally, evidence suggests that these “traditional” values, which are more common among minorities, may encourage more supportive family environments and lower rates of high EE. Much of the research used to inform the development of CIT-S was based on Hispanics. However, the treatment is not specific to any particular racial or cultural group and we believe it will benefit Caucasians and minorities alike.

CIT-S incorporates therapeutic components informed by cross-cultural research including modules on spirituality and family collectivism, as well as techniques that have demonstrated efficacy in treating families of patients with schizophrenia, such as psychoeducation and communication training. CIT-S is a fifteen-week intervention comprising five segments, each lasting for three sessions. Each segment of CIT-S covers a different topic and is guided by a series of handouts. Between-session homework is assigned for family members to practice the skills that are addressed during therapy.

*Family collectivism.* The first treatment segment of CIT-S is family collectivism. The objective of this module is to help family members develop the perspective that they are part of a unified team working toward common goals. This is attempted through a variety of approaches. First, the therapist begins treatment by asking each family member to verbalize their expectations and goals for treatment. This provides an opportunity to emphasize commonalities, as most family members report that getting along better and promoting the patient’s health are shared priorities. The collectivism handout used in this module includes a series of questions to generate a discussion about each participant’s

identification with their family unit and the way they function within this unit. In-session activities and homework assignments associated with this module include preparing personal narratives regarding how each family member feels they contribute to the general family functioning. Through these narratives, family members begin to consider the ways they impact the family system. These narratives are also helpful in generating ideas about improving family functioning. The therapist often encourages family members to identify specific behaviors of other members that they value and believe contribute to the well-being of the family.

Family members are also provided a therapeutic environment to express any dissatisfaction with roles they have acquired or lost as a result of schizophrenia. For example, many caregivers complain that their role as a parent becomes extended when an adult child is mentally ill. Discussing these topics openly often offers an opportunity for perceptions of family unity to increase. For example, patients may share that they too feel chagrin that their caregivers are permanently stuck in a parenting role and that they are also unhappy with forever remaining in the role of dependent child. Through this module, the therapist works to unify family members by emphasizing the commonalities between them and deemphasizing family differences. We predicted that this type of approach would foster a sense of interdependence, or interconnectedness, among family members. It was also expected that self-conscious emotions related to the illness would decrease as the focus was shifted from any one person's role in the illness to the ways the family system works as a whole to impact symptoms.

*Education.* The second module of CIT-S is psychoeducation. This segment is based on previous psychoeducation interventions developed by Falloon, Boyd, and

McGill (1984) and Miklowitz and Goldstein (1997). The objective of this segment is to provide succinct but thorough information regarding schizophrenia. Family members are educated on the common symptoms of schizophrenia, and are taught to accurately identify the prodromal symptoms that may be present before a relapse. Additionally, family members are given information on the known causes of schizophrenia and its exacerbating factors, including genetics, neurochemistry, and environmental factors. Finally, family members learn about the ways that family environments and communication may influence the patient's course of illness.

The education module serves multiple purposes. First, receiving education on the signs and symptoms of the illness is expected to allow family members to engage in relapse prevention and intervention planning as a team. For example, caregivers and patients can identify symptoms that are typically present or exacerbated for the patient before the onset of a psychotic episode. The family can then create a plan to respond to these signs in the event that they do occur in the future. This collaborative planning is expected to foster a sense of teamwork and promote the perception that schizophrenia is a stressor that can be managed by the whole family. As family members learn about the biological origin of schizophrenia and the wide range of symptoms that may present with the illness, they potentially may be less likely to respond to patient behaviors that they do not understand in a critical or abrasive manner. For example, many caregivers are not familiar with the negative symptoms of schizophrenia such as flat affect, avolition and poverty of speech. Instead, the positive symptoms of schizophrenia, such as hallucinations and delusions, are the typical symptoms that come to mind when they

think of the illness. As a result, symptoms such as lack of motivation or poor hygiene are often attributed to personality traits such as laziness or lack of judgment.

Family members are also educated about the critical role of stress in exacerbating symptoms of the illness, and the ways that environmental factors may interact with genetic vulnerabilities to influence the presentation of the disorder. Finally, information is provided regarding the detrimental effect of substance use on the onset of the illness, prognosis, and severity of symptoms. Discussing the influence of these external factors on the illness provides the therapist an opportunity to reiterate that family members may do several things to assist the patient in their recovery. The therapist emphasizes that each family member plays a role in maintaining a healthy home environment for the patient, thus reinforcing the perception of a working team. Therefore, we expected that levels of shame and guilt/self-blame would be reduced as misconceptions about the illness were clarified.

*Spiritual coping.* The third module of CIT-S, spiritual coping, is aimed at assisting family members in accessing any spiritual or existential beliefs that may serve as a resource in coping with the illness. The segment begins by asking family members to provide a history of their spiritual beliefs, values and practice. The handout for this module consists of questions to guide a discussion regarding family member's beliefs about God or a supreme being, perceptions of morality, and their views on the meaning and purpose of life. Additionally, they are asked about the role of any spiritual practices that they currently use or would like to use. These practices include concrete behaviors such as prayer, meditation, volunteerism, or attending religious services. Additionally, discussions consist of practices such as forgiveness, kindness and empathy. Family

members are encouraged to engage in practices outside of treatment that are identified as being potentially therapeutic and then discuss these experiences in session.

The spirituality module is completed with every family, regardless of their expressed religious orientation, or lack of a religious orientation. Therapists make no attempt to instill or push any particular religious stance during this segment. Instead, the objective is for family members to consider the potential resources that may exist in their spiritual or existential beliefs. Family members who do not subscribe to a particular religious practice or do not want to discuss their religious beliefs complete many of the same exercises as religious families using a parallel set of handouts that do not specifically reference “God” or “religion.” Instead, these family members engage in existential exercises such as philosophical readings or mindfulness meditation and a discussion of spiritual concepts such as empathy and appreciation.

During the spirituality module the therapist works to reframe any maladaptive uses of religion or spirituality, such as the belief that schizophrenia in a loved one is a punishment from God for a previous wrongdoing that the caregiver may have committed. Such a belief may lead a caregiver to experience feelings of responsibility, shame and guilt for their loved one’s illness. Therapists do not directly challenge any religious or spiritual beliefs held by family members, but instead work to guide participants in adopting more adaptive uses of religion. For example, therapists may ask the family members to think about how they have found meaning in caregiving or to consider the ways that God uses the struggles of mental illness to teach patience or build virtue. Engaging in activities as a family, such as attending religious services or volunteering, may foster a sense of unity and interdependence among family members. Thus, we

expected that self-conscious emotions would decrease as participants addressed maladaptive religious/spiritual conceptualizations about mental illness that hinged upon personal responsibility.

*Communication training.* The final two modules of CIT-S, communication training and problem-solving, are based largely on approaches that have strong empirical support for assisting families of patients with severe mental illnesses (Falloon, Boyd & McGill, 1984; Miklowitz & Goldstein, 1997). In communication training, family members are taught a set of skills to assist them in providing support for one another more effectively. Specific skills that are targeted in this module include active listening, expressing positive regard, and making requests for behavioral change. These skills are practiced in session through discussion and role-play. The communication module provides the patient the opportunity to discuss with their caregivers an appropriate means to communicate their illness that reduces stress for all family members. Additionally, caregivers are guided to shift the focus of their communication regarding illness-related stressors from the individual as a whole to specific behaviors. We expected each of these exercises in communication to increase perceptions of interconnectedness among family members.

*Problem-Solving.* In the final phase of treatment, family members practice problem-solving skills to enhance their ability and self-efficacy in managing the challenges associated with schizophrenia. Participants are taught to identify problems, brainstorm all possible solutions without judgment, and then evaluate each of these ideas to arrive upon the optimal solution for the chosen problem. A strategy is then put in place to carry out the solution. Through these exercises, family members learn to view the daily

challenges associated with mental illness as external problems that they could tackle as a united team. This is an opportunity for family members to work through challenges that have arisen during the course of the intervention. For example, the theme of medication compliance is a concern for many family members. The problem-solving segment provides an opportunity for patients and caregivers to strategize a concrete plan that is feasible and acceptable to all family members. Each of the final two modules of CIT-S promote increased family cohesion and interdependence by fostering a sense of mutual support and acceptance and promoting a teamwork approach to managing the stressors related to the illness. Therefore, we expected that caregivers' personal sense of responsibility or blame would decrease, and their perceived interconnectedness would increase in this module.

#### *Psychoeducation Comparison*

The psychoeducation comparison condition consists of three sessions of psychoeducation using the same format as the education segment of CIT-S. Information is provided about the known causes and exacerbating factors of schizophrenia including biology, life stress, and interpersonal factors. A psychoeducation control condition was chosen in order to address whether or not CIT-S leads to clinical improvement above and beyond ordinary clinical management. As reviewed, short-term family psychoeducation has demonstrated improved patient functioning as well as benefits for caregivers. Although it is used too infrequently, it is currently the standard practice for family treatment of schizophrenia. Because short-term psychoeducational sessions have demonstrated efficacy for both patients and their relatives (Dixon, Adams, & Luckstead, 2000), the psychoeducation condition was not considered to be a placebo condition.

*Measures*

Copies of all measures except for the SCID-I/P may be found in the Appendix.

*Eligibility for current study.* The Structured Clinical Interview for the DSM-IV Axis I Disorders, Version 2.0, patient edition (SCID-I/P; First, Spitzer, Gibbon, & Williams, 1996) is a semi-structured interview used for determining diagnosis with patients with Axis I disorders. The psychotic symptoms section was used in this study to determine diagnoses of schizophrenia/schizoaffective disorder. The SCID-I/P has shown high inter-rater reliability for symptoms and diagnosis (Ventura, Liberman, & Green, 1998). To assess inter-rater reliability of the SCID in the current study, all interviewers as well as the study's Principle Investigator watched six videotaped interviews and independently rated each item to determine an overall diagnosis. Inter-rater agreement using Cohen's Kappa was 1.0.

*Caregiver Burden.* Family member burden was assessed using The Modified Burden Assessment Scale for Families of the Seriously Mentally Ill (BAS, Reinhard & Horowitz, 1994). The BAS contains 19 items and two distinct subscales that assess the objective and subjective consequences of caregiving. Ten objective burden items measured potentially observable behavioral effects of caregiving in four areas: financial problems, limitations on personal activity, household disruption, and social interactions. Nine subjective burden items measured the feelings attitudes and emotions specifically related to caregiving in multiple domains (e.g. stigma, grief). The BAS demonstrated very good reliability at baseline with a total Chronbach's alpha of .951 (.983 for English and .925 for Spanish). Overall the BAS demonstrated good reliability at termination with a total Chronbach's alpha of .874 (.881 for English and .862 for Spanish).

*Interdependence.* Interdependence was rated using Singelis' (1994) "Measurement of Independent and Interdependent self-construal Scale (SCS)." The full scale is a 24-item instrument designed to assess independent values, as reflected by an emphasis on the separateness and uniqueness of the individual and interdependent values, as reflected by an emphasis on connectedness and relatedness. For this study we were interested in the construct of interdependence and thus only used the 12-item Interdependent subscale. Respondents were asked to indicate their agreement with the items in a 7-point Likert-type format (1 = strongly disagree, 7 = strongly agree). Scores can range from 12 to 84 on this subscale, with higher scores indicating a more interdependent self-construal. At baseline, the interdependence subscale of the SCS demonstrated excellent internal reliability with a total Chronbach's alpha value of .985 (.989 for English and .940 for Spanish). This subscale demonstrated adequate internal reliability at termination with a total Chronbach's alpha value of .812 (.832 for English and .854 for Spanish).

*Shame and guilt/self-blame.* Weisman de Mamani's (2007) *Self-conscious Emotions for Schizophrenia Scale* assessed shame and guilt/self-blame about having a relative with schizophrenia. Relatives reported the degree to which having a relative with schizophrenia is a source of shame and blameworthiness to them. Responses ranged from 1 (Not at all true) to 7 (Very true), with higher scores reflecting a greater degree of the self-conscious emotion in question.

#### *Statistical Analyses*

All preliminary analyses took place using SPSS. Prior to conducting primary analyses, the distribution of all variables were examined for normality and homoscedasticity of residuals. Additional analyses were conducted to examine the

relationship of demographic variables (age, gender, ethnicity, family member type) to primary variables of interest. Additionally, pretreatment variables, both demographic and primary, were compared between the CIT-S and TAU conditions in order to examine the effectiveness of the randomization and ensure equivalence across treatment conditions. All of the primary analyses took place using Structural Equation Modeling (SEM) in Mplus. We used multilevel modeling to analyze individual family members nested within families as per guidelines provided by Raudenbush and Bryk (2002). This approach allowed us to increase our sample size and overall statistical power, and took into account any bias in standard errors and statistical tests resulting from the non-independence of observations (Krull & MacKinnon, 2001). Estimates of model fit were obtained using the Satorra-Bentler scaled correction (Satorra, 2000) to account for possible multivariate abnormality. For each of these analyses, model fit was evaluated using four fit statistics: a non-significant value for the Chi-square test of model fit ( $\chi^2$ ),  $\geq .95$  for the comparative fit index (CFI),  $\leq .06$  for the root mean square error of approximation (RMSEA), and  $\leq .09$  for the Standardized Root Mean Squared Residual (SRMR).

## Chapter 3: Results

### *Preliminary Analyses*

*Missing data.* Missing data were present for all variables of interest and there was no indication of a systemic response bias. The full information maximum likelihood estimation method was used to account for missing observations. Using this method, all cases in the sample were partitioned into subsets with the same patterns of missing observations. Statistical information and structural parameters were obtained from each subset, and each case remained in the analysis. The maximum likelihood estimation method has been found to outperform traditional methods of accounting for missing data in structural equation modeling (Kline, 2005).

*Study Variables.* All primary study variables were examined for both outliers and normalcy. One outlier was found for results on the SCS based on standardized residuals, Cook's D, as well as dfBeta values. This observation was removed for subsequent analyses. Curran, West, and Finch (1996) recommend concern about non-normality if skewness is above 2 and kurtosis is above 7. Using this criteria, transformations were not necessary for any study variable using these criteria.

*Demographic Variables.* Next, the relationship of demographic variables (age, gender, ethnicity, type of relative) to primary variables of interest was examined. Table 2 presents descriptive data for the primary variables of the study. Pearson's r correlations were conducted with the main variables of study (caregiver burden, interdependence, shame and guilt/self-blame) and with continuous demographic variables (age). Age was not found to be significantly associated with any of the primary variables of interest in this study.

Independent-samples t-test statistics were performed in order to assess whether main variables of study were significantly associated with nominal demographic variables with two groups (gender). Gender was found to be significantly associated with both shame ( $t= 13.78, p < .01$ ) and guilt/self-blame ( $t=18.738, p < .01$ ) related to having a relative with schizophrenia such that females demonstrated higher levels of both of these self-conscious emotions than males. As a result, gender was controlled for in subsequent analyses.

One-way ANOVA's were used to assess any significant relationships between primary variables and nominal demographic variables with more than two groups (type of family member, ethnicity). Interdependence was found to differ significantly according to ethnicity ( $F = 4.28, p < .01$ ). Post hoc analyses indicated that Hispanics demonstrated significantly higher levels of interdependence compared to both Caucasians and African Americans. Caucasians and African Americans did not differ significantly from each other. Additionally, significant ethnic differences were found for levels of shame regarding having a relative with schizophrenia ( $F = 7.07, p < .01$ ). Specifically, African Americans demonstrated significantly higher levels of shame when compared with Caucasians. Hispanics did not significantly differ from African Americans nor Caucasians. Based on these findings, ethnicity was controlled for in subsequent analyses. No significant differences were found for primary variables of study according to family member type.

Finally, pretreatment variables, both demographic and primary, were compared between CIT-S and psychoeducation condition in order to examine the effectiveness of the randomization and ensure equivalence across treatment conditions. A series of two-

tailed t-tests (for continuous data) and Fisher's exact tests (for categorical data) were used to examine baseline variables. No group differences were found between treatment conditions for any primary variables at baseline demonstrating effective randomization. Means for both baseline and termination levels of primary variables according to CIT-S versus psychoeducation can be found in Table 3.

### *Primary Analyses*

As mentioned, all of the primary analyses took place in Mplus using SEM. Our data was modeled using two levels. The Level 1 equations contained the intercepts and slopes for individual caregivers. At Level 2, the average family intercepts and slopes were modeled by overall averages and corresponding variance components that captured the variability of the family. This modeling structure was used for all primary analyses in this study.

*Hypothesis A.* The first set of analyses was conducted in order to evaluate the ability of CIT-S to influence multiple outcome measures for caregivers of patients with schizophrenia when compared to the psychoeducation condition. First, a confirmatory factor analysis was run to confirm the proposed measurement model. A latent variable named Self-Conscious Emotions was specified by termination levels of shame and guilt/self-blame loaded while controlling for baseline levels of these variables. Fit indicators demonstrated this model did not fit the data,  $\chi^2(5) = 22.53$ ,  $p = .000$ , CFI = .752, RMSEA = .334, SRMR = .083. Additionally, factor loadings for both variables were less than .8 indicating inadequate fit. As a result, shame and guilt/self-blame were examined separately in all subsequent analyses.

Next, a model was specified regressing termination levels of caregiver burden, shame, guilt/self-blame and interdependence (controlling for each of these variables at baseline) on the level 2 variable of treatment condition. This was considered the baseline model for the first hypothesis as it contained all variables of interest. Intraclass correlations for each outcome variable were used to calculate design effects. Design effects for each variable were greater than 2, indicating that clustering of the data was appropriate for this data set. Examination of the between-level estimates of the model results demonstrated that treatment condition significantly predicted termination levels of caregiver burden ( $\beta=2.058$ ,  $p < .01$ ), and guilt/self-blame ( $\beta=.397$ ,  $p < .05$ ), while controlling for baseline values of these variables. Treatment condition was not found to significantly predict termination levels of shame ( $\beta=.271$ ,  $p = .274$ ), nor interdependence, ( $\beta=-.109$ ,  $p = .638$ ). Parameter estimates for this model are reported in Table 4. In an effort to maintain the most parsimonious model going forward, interdependence was dropped from subsequent analyses. Examination of the means for the termination variables for participants in CIT-S versus psychoeducation demonstrates that values are in the expected direction. That is, mean levels of termination guilt/self-blame and burden were significantly lower for participants who completed CIT-S when compared to those who completed psychoeducation. Additionally, while not significant, mean levels of termination shame were lower for participants who completed CIT-S compared to psychoeducation.

*Hypothesis B.* Multilevel structural equation modeling (MSEM) was used to assess whether changes in the self-conscious emotions of shame and guilt/self-blame partially mediated the relationship between treatment type and caregiver burden. MSEM was

chosen to conduct these analyses instead of traditional multilevel modeling (MLM) for several reasons. This approach has been found to reduce error due the conflation of between and within group effects as well as unreliable cluster means that characterize multilevel mediation within the MLM framework (Preacher et al., 2011). Additionally, MSEM is feasible as it is easily available using *Mplus*. As in the previous set of analyses, individual caregiver variables were measured at Level 1, and caregivers nested within families were measured at Level 2. Treatment condition, the independent variable for all analyses, was identified as a Level 2 variable since participants were randomized to treatment conditions as a family. All other mediational and outcome variables (shame, guilt/self-blame, and caregiver burden) are individual characteristics or behaviors, and thus were tested at Level 1. Given this design, a  $2 \rightarrow 1 \rightarrow 1$  mediational model was specified as recommended by Krull and MacKinnon (2001) to appropriately model the error structure of our clustered data.

When specifying the  $2 \rightarrow 1 \rightarrow 1$  MSEM model, treatment condition was identified as the between group variable. Level 1 variables of termination shame, guilt/self-blame and caregiver burden were not identified within the syntax as between or within group variables, which allowed them to have both between and within group variance. The specified cluster variable was each participant's family number. The model for within group effects was specified to regress caregiver burden on termination shame and guilt/self-blame. The model for between group effects was specified to regress termination shame, guilt and caregiver burden on treatment condition, as well as termination caregiver burden on termination shame and guilt/self-blame. Slopes for each of these regressions were identified in order to compute indirect effects. Between-group

indirect effects were calculated using the slopes identified for the paths between each mediator and treatment condition, as well as the slope of both mediators from treatment condition to caregiver burden.

The mediation model examined both shame and guilt/self-blame as mediators of the relationship between treatment condition and caregiver burden. This model fit the data as demonstrated by indicators of model fit,  $\chi^2(13) = 13.762$ ,  $p = .106$ , CFI = .915, RMSEA = .05, SRMR = .083. When examining the specific paths, treatment condition was found to significantly predict termination levels of guilt and caregiver burden. Treatment condition did not significantly predict termination levels of shame. This was consistent with previous analyses. Guilt/self-blame was found to significantly predict termination levels of caregiver burden ( $\beta = 1.819$ ,  $p < .05$ ). Shame was not found to predict caregiver burden at termination ( $\beta = .179$ ,  $p = .858$ ). Finally, the new/additional parameters introduced to the model were examined. A significant indirect effect was found between treatment condition and termination caregiver burden via termination guilt/self-blame ( $\beta = .497$ ,  $p < .05$ ) indicating a partial mediation effect. The indirect effect between treatment condition and termination caregiver burden via shame, however, was not significant, ( $\beta = -.176$ ,  $p = .860$ ). The full model including covariates is depicted in Figure 2. Parameter estimates for the mediation model are reported in Table 5.

## Chapter 4: Discussion

The overarching aim of this study was to test whether a family-focused, culturally-informed treatment for schizophrenia (CIT-S) was effective in lowering distress for caregivers of patients with this illness. The study also attempted to assess whether changes in three specific variables (shame, guilt/self-blame and interdependence) might account for some of the therapeutic benefits of this intervention. CIT-S was compared against a three-session psychoeducation condition. Below, findings from this study will be discussed. Next, study limitations, future research directions, and final conclusions will be offered. Finally, a clinical vignette is included to illustrate how CIT-S targets the primary constructs of this study. Several qualitative examples are also provided in an Appendix.

### *CIT-S and Caregiver Burden*

With respect to our first study aim, results indicated that CIT-S significantly lowered levels of caregiver burden when compared to our psychoeducation condition. This demonstrates the potential for a family-focused intervention incorporating culturally-informed components to have a significant positive effect on schizophrenia caregivers. As reviewed, the toll that schizophrenia takes on family members is severe and most caregivers report high degrees of objective and subjective burden (e.g., Barrowclough et al., 1996; Winefield & Harvey, 1993). While other psychosocial interventions for schizophrenia have been developed to incorporate family members, levels of burden remain considerable in this population (Awad, 2008). One explanation for these existing levels of distress may be that many of the current family treatment programs for schizophrenia are focused on improving patient outcomes, such as relapse

rates and symptom severity, but fail to view caregiver well-being as a central area of focus (Cuijpers, 1999; Lam, 1991). CIT-S includes a specific objective to alleviate caregiver burden (in addition to improving patient functioning) and our study results suggest that we were successful in this aim.

*CIT-S and Guilt/Self-blame*

Also in line with hypotheses, caregivers who completed CIT-S endorsed significantly lower levels of guilt/self-blame about having a relative with schizophrenia at termination when compared to those who completed psychoeducation only. As reviewed, individuals feel guilt/self-blame when they take ownership or blame for a negative event. In the context of CIT-S, schizophrenia caregivers may experience this emotion by holding themselves responsible for their loved one's illness or illness-related stressors. Our baseline information indicates that caregivers are experiencing a substantial amount of guilt/self-blame regarding having a relative with schizophrenia. Taking responsibility for the consequences of this illness might allow caregivers to understand or conceptualize an otherwise inexplicable or unpredictable situation. However, guilt/self-blame can become maladaptive when one takes ownership for an uncontrollable event like schizophrenia. These attributions can then be associated with excessive self-criticism or the assumption of responsibility for all wrongs. Our results demonstrate that CIT-S was successful in addressing these maladaptive cognitions of responsibility beyond what was offered by psychoeducation about the illness. This finding has important implications for patients, as guilt/self-blame has been found to be a significant predictor of high-EE communication in schizophrenia caregivers (Wasserman et al., 2012).

*CIT-S and Shame*

Surprisingly, we did not find that shame and guilt/self-blame loaded on to latent variable in our sample. While this is not in line with our study hypotheses, it is somewhat consistent with prior research differentiating these constructs (e.g. Tangney et al., 1996). As reviewed, research indicates that shame is a more distressing emotion than guilt/self-blame, and is often associated with internal attributions for negative events while guilt/self-blame is typically linked to external causes (Tangney, 1995). Though both are self-conscious emotions, perhaps shame and guilt/self-blame are manifested differently in the context of caregiving. Additionally, treatment condition was not found to predict termination levels of shame in this study. It is possible that shame is more deeply-rooted or intractable when compared to other self-conscious emotions. Research suggests that shame-proneness may be more stable and trait-like when compared to guilt-proneness and consequently more difficult to modify (Tracy & Robbins, 2006). Thus, the experience of shame related to having a relative with schizophrenia could require a more extensive intervention than was offered by CIT-S.

*CIT-S and Interdependence*

Contrary to hypotheses, caregivers who terminated CIT-S did not demonstrate increased interdependence when compared to those who completed the psychoeducation condition. It is possible that there was not enough variability in our sample to detect changes in this construct. In general, participants in this study endorsed high levels of this value, both at baseline and termination. Additionally, 60% of our caregiver sample identified as Hispanic. As previously mentioned, Hispanics as an ethnic group reported significantly higher levels of interdependence when compared to other ethnic groups in

our sample. This result could also be due to a self-selection effect. It is likely that caregivers who volunteer to participate in a weekly, family therapy study value interdependence more than those who are unwilling to make such a significant commitment to spend time with their family.

#### *Self-Conscious Emotions as Mediators*

It was hypothesized that changes in levels of shame and guilt/self-blame would partially mediate the relationship expected between treatment type and caregiver burden. Specifically, we predicted that decreased levels of self-conscious emotions would account for the reductions of caregiver burden expected for participants who completed CIT-S relative to those who completed psychoeducation only. In line with our study hypotheses, treatment condition was found to significantly impact levels of caregiver burden not only directly, but also indirectly, via termination levels of guilt/self-blame. This significant indirect effect indicates that guilt/self-blame partially mediated the relationship between treatment condition and caregiver burden in this sample. Our finding demonstrates the underlying influence of self-conscious emotions on caregiver distress. Guilt/self-blame has been recognized as a common emotion experienced by schizophrenia caregivers. These results suggest that addressing the cognitions or attributions associated with caregivers' experience of guilt/self-blame may be an effective path to also decrease the high levels of caregiver burden that tend to plague this population. Targeting guilt/self-blame in treatment has the potential to not only benefit relatives by reducing their perceived burden, but indirectly benefit patients by lowering high-EE communication in caregivers.

### *Preliminary Findings*

While not directly related to the primary hypotheses of the current study, interesting preliminary findings emerged that may be relevant for future work in the area of schizophrenia caregivers. First, women were found to have higher levels of both shame and guilt/self-blame when compared to men in this sample. This is consistent with a body of literature demonstrating that women generally endorse higher levels of self-conscious emotions as well as guilt-proneness and shame-proneness when compared to men (e.g. Benetti-McQuoid & Bursik, 2005). Similarly, some gender role researchers posit that the desire for interpersonal connection and an awareness of others' mood states falls within the parameters of traditional socialization for women when compared to men (Umberson et al., 1996). Therefore, it is possible that women may be more primed to feel guilt/self-blame for behaviors or actions that affect others. Finally, previous studies suggest that the traditional female gender role is more likely to be associated with depression, lower self-esteem, and poorer coping skills than the conventional male gender role (Bursik, 1995; Whitley, 1983). Each of these experiences has been found to be positively associated with the experience of shame (Tangney, 1995).

With respect to ethnicity, Hispanics endorsed higher levels of interdependence than other ethnic groups in this sample. This finding supports substantial research demonstrating that Hispanics as an ethnic/racial group are more likely than other groups to value interdependence among family members (Matsumoto, 1997). In fact, in many Western societies, there is a strong emphasis on remaining autonomous and deriving one's sense of self-esteem from achievements that result from internal attributes, such as one's personality traits, abilities, and intelligence. Non-Western ethnic/racial groups, on

the other hand, are more likely to prioritize the needs and standards of relevant social groups above and beyond one's personal needs. Not surprisingly, one's identified family is likely to be a primary group of importance.

Additionally, African Americans endorsed higher levels of shame than other ethnic groups in this sample. Research in the area of racial identity indicates that, due to the often chronic and constant exposure to society's negative messages, African Americans are more likely than other racial groups to internalize a sense of inferiority (Steele, 1990; Steele & Aronson, 1995). Subsequently, as a group African Americans may be more prone to feeling shame than other racial groups when confronted with serious mental illness in the family.

#### *Limitations and Future Directions*

There were a number of limitations to the present study. First, the sample was predominantly Hispanic and mothers of patients. Thus findings from this study may not generalize to a broader sample of relatives. Follow-up research with a larger and more diverse sample is needed. Future study is also needed to better understand the demographic and ethnic/racial patterns observed in this study. It will be important to clarify the mechanisms that may account for higher levels of self-conscious emotions in women and African American caregivers when confronted with a loved one with schizophrenia.

Another limitation to our study was having a somewhat restricted range for the measure of interdependence. In general, participants endorsed high levels of this value. This finding is not entirely surprising. As mentioned, the majority of this sample was Hispanic, an ethnic group much more likely to identify as interdependent when compared

to other ethnic/racial groups. Additionally, all of the caregivers participating in this study were willing and often eager to enroll in a family-focused psychosocial intervention which required multiple, extensive interviews and a commitment to participate in up to 15 weeks of treatment. Thus, we expect that most caregivers were likely to be committed to the well-being and cohesion of the family system. While high levels of interdependence are desirable in a clinical sense, a limited range on this construct may have impeded our ability to observe changes in this variable or to see relationships with other constructs (e.g., caregiver burden). In the future, using a larger and more varied sample may provide more range in terms of this construct.

Our sample also had a restricted range in levels of shame, such that most relatives reported experiencing relatively low levels of shame about having a loved one with schizophrenia. It is possible that caregivers willing and motivated to participate in a research study with their family are more accepting of their relatives' illness, and therefore less representative of the shame experienced by caregivers of mental illness in the general population. Alternatively, Ryan (1993) argued that many individuals defend against the conscious awareness of shame. Perhaps caregivers in this study were not fully aware that they were feeling ashamed of having a loved one with schizophrenia. Future research should employ more objective measures of shame, such as the Test of Self-Conscious Affect (TOSCA; Tangney, Wagner, & Gramzow, 1989), in order to capture elements of shame that participants are unwilling or unable to acknowledge directly.

The length of our comparison condition may also be seen as a study limitation as CIT-S is 12 weeks longer than psychoeducation. While it is exciting that CIT-S is able to outperform a treatment that has demonstrated effectiveness and that is currently a gold

standard (only 7% of patients get any family therapy), it will be critical to eventually examine whether CIT-S can outperform other established interventions, such as Family Focused Therapy (Miklowitz & Goldstein, 1997) that are matched in length.

There were also a few limitations to our study measures. The first concerns the Interdependence subscale of the SCS. It is possible that our participants had difficulty relating to some of the items in this measure. Each item of this subscale presents a hypothetical social situation (“I would offer my seat on a bus to my professor”), and several of these scenarios may not have been applicable to many of our participants. In the future, it would be beneficial to reassess study hypotheses using other self-construal measures such as the Sixfold Self Construal Scale (Harb & Smith, 2008), which assesses six subcategories of self-construal.

Additionally, the constructs of shame and guilt/self blame, assessed using the Self-directed Emotions for Schizophrenia Scale, were measured with just one item each. Longer scales tend to be more reliable and valid and should be considered when conducting follow-up work in this area. Future studies that measure both specific and dispositional measures of self-conscious emotions may offer the greatest insights into how self-directed emotions relate to caring for a person afflicted with mental illness.

Future research is needed to address how to reduce shame in treatment for schizophrenia caregivers. It is possible that more directive interventions are necessary to identify the critical and devaluative cognitions associated with this emotion. Studies in the area of shame related to PTSD in Veterans indicate that a focus on self-forgiveness and compassion in interventions may be effective in reducing proneness to shame (Lee, 2005). Additionally, treatments that incorporate mindfulness training have been shown to

be successful in reducing levels of shame in a non-clinical population through the promotion of acceptance of self-critical thoughts and feelings (Neff et al., 2006). Further investigation is needed to evaluate whether these techniques would be useful in reducing shame associated with having a relative with schizophrenia.

### *Conclusions*

Our study findings demonstrate that CIT-S has the potential to reduce burden for schizophrenia caregivers. This has important clinical implications given the high levels of distress endorsed by this population. Additionally, one of the vehicles by which this may occur is lowering levels of guilt and self-blame. Reducing caregiver guilt/self-blame and burden are important outcomes in their own right. However, we believe these findings may extend beyond caregivers. As previously discussed, guilt/self-blame in caregivers has been found to be predictive of higher levels of EE. Therefore, CIT-S's ability to decrease this self-conscious emotion for caregivers has possible indirect benefits for patients as well. Below we will terminate with a qualitative example to illustrate how CIT-S may reduce guilt/self-blame and burden.

### *Clinical Vignette*

Luis and Mary, the parents of a 30 year-old female diagnosed with schizophrenia, were randomized to CIT-S after responding to a recruitment advertisement on the metrorail and completing a baseline assessment. Both parents are professionals in their mid-60's, of Cuban descent and identified as practicing Catholics. Their daughter, Katherine, first experienced symptoms of schizophrenia during her second year of college at a prestigious university. In the twelve years since her initial diagnosis, Katherine had been hospitalized over fifteen times and arrested eight times for illness-related behaviors.

During their baseline interview, Luis and Mary endorsed high levels of objective and subjective burden related to caregiving. Their family's economic situation was significantly impacted by costs associated with their daughter's illness. Both parents had not been able to travel at the same time for over a decade as one parent needed to be available in case of an emergency. They also reported that caregiving had greatly limited their social life and opportunities for leisure time or recreational activities. In their first session of CIT-S, each parent endorsed experiencing acute levels of guilt and responsibility for their daughter's persistent illness. Therefore, primary goals for this CIT-S family included addressing the high levels of distress associated with caregiving and reducing the parents' feelings of self-blame.

The therapist began by assessing how Luis and Mary believed their roles within the family had changed due to Katherine's illness. Mary stated that she felt like her daily life was determined by her daughter's illness. She reported that her daughter called her over fifty times a day, frequently requesting different items such as cigarettes or food, and often reporting suspicious activity related to paranoia. Mary spent a substantial amount of time responding to these calls and catering to her daughter's requests. Mary attributed her behavior to a sense of responsibility for Katherine's illness. Throughout this module and subsequent sessions, the therapist asked Mary to consider whether or not the behaviors prompted by this guilt were effective or beneficial. Mary reported that they often reduced her "Cuban guilt" in the short term because Cuban women are taught to do everything within their power to help their children. Through treatment however, Mary eventually came to the conclusion that consistently responding to these requests was not helpful for herself or Katherine. This was underscored in the Education module when Luis and Mary

learned about Emotional Over-Involvement, a dimension of Expressed Emotion.

Research in this area indicates that schizophrenia patients have a poorer course of illness when their caregivers are too involved or self-sacrificing.

The theme of parental guilt surfaced frequently and was addressed throughout treatment. For example, the family reported that learning about the biochemistry and genetic components of schizophrenia in the Education module made them feel less responsible, and alleviated their concern that Katherine's illness was a result of bad parenting. Furthermore, during the Spirituality module the therapist asked Luis and Mary how Catholicism informed their understanding of their daughter's illness and their role as caregivers. They disclosed that, within the framework of their religion, they attributed Katherine's schizophrenia to retribution for previous sins they had committed. They stated that the worst punishment imaginable was watching their child suffer. The therapist asked the family to evaluate how carrying the responsibility for their daughter's illness served them as caregivers. Without challenging their religion, the therapist pointed out that this perception of punishment may underlie much of the guilt related to caregiving that they endorsed. Over the next sessions, the therapist worked with the couple to reframe this conceptualization to an understanding of their daughter's illness that did not hinge on punishment or blame. For example, the family discussed Catholicism's emphasis on serving others, and the virtue found in taking care of those in need. The therapist asked the family to bring in scripture quotes that resonated with them and addressed this call to service (e.g. Jesus washing the feet of his disciples). The therapist also asked the parents to consider what positive things their daughter's illness had brought them. Luis and Mary stated that caring for Katherine had led to the

development of greater empathy for others with mental illnesses as well as a strong desire to advocate for this community. Both parents became involved in schizophrenia-related advocacy groups and appeared empowered by this experience.

By the end of treatment, Luis and Mary reported feeling better equipped to manage the stressors associated with caring for their daughter. The Collectivism module and subsequent problem solving exercises had motivated Luis and Mary to reach out to other key family members and loved ones for assistance in caring for Katherine. They viewed this as consistent with their cultural worldview in that good Cuban families stick together and help one another in times of need. Mary began designating the responsibility of fielding some of her daughter's frequent phone calls to other family members at specific points of time. This allowed Mary to silence her phone during therapy sessions and at least one night a week during dinner with Luis. The delegation of these small duties increased the amount of time that Luis and Mary could spend on personal activities, and reduced the perception that they were carrying the sole responsibility for their daughter's illness. As an indirect benefit, Luis and Mary also reported feeling much closer and connected to individual family members who pitched in to help out. They described feeling reassured knowing they were part of a strong and cohesive family unit.

In brief, Luis and Mary's perceived guilt over possibly causing their daughter's illness and/or not being able to help her find a cure was a primary topic addressed throughout CIT-S. Many of their cognitions of self-blame for Katherine's schizophrenia had prevented them from seeking assistance and delegating tasks related to caregiving. Additionally, the perception that they were solely responsible for their daughter's illness, and in fact were being punished for it, had limited their motivation to look for support

systems in their community and within their family, and kept them from finding reassurance in their religion. As a consequence of their reduced guilt and ability to share their caregiving burdens with others, Luis and Lily terminated treatment feeling much less burdened and more hopeful about the future

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Figure 1

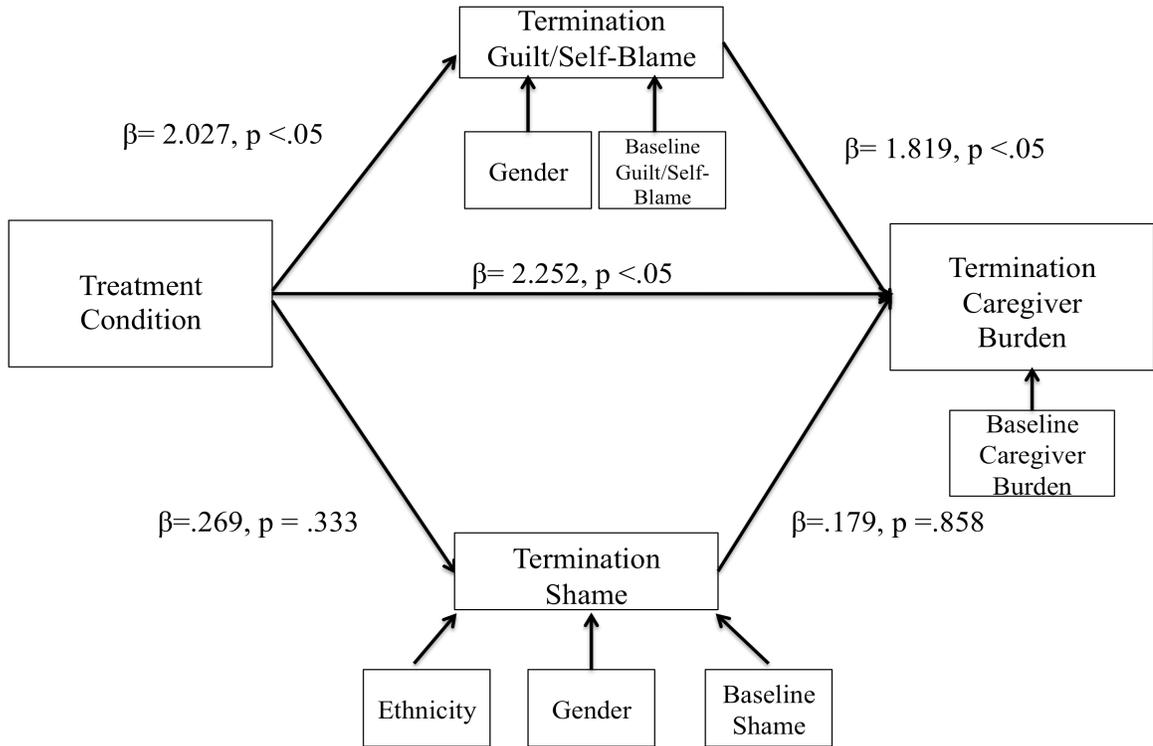


Table 1. Frequencies for categorical data (N = 113)

Variable	Frequency
<b>Type of Relative</b>	Mother = 43 Father = 25 Significant Other/Spouse = 9 Sister = 12 Brother = 10 Offspring = 4 Aunt = 3 Grandmother = 3 Cousin = 3 Step-father = 1
<b>Gender</b>	Female = 71 Male = 42
<b>Ethnicity</b>	Hispanic = 67 Caucasian = 31 African American = 12 Other = 3
<b>Primary language</b>	English = 81 Spanish = 32
<b>Treatment Assignment</b>	CITS = 64 Psychoeducation = 49

Table 2. Descriptive Data for Continuous Variables (N = 113)

Variable	Mean	Standard Deviation	Range	Min.	Max.
Age	53.24	15.04	72.00	14.00	86.00
<i>Baseline</i>					
Shame	2.63	1.76	6.00	1.00	7.00
Guilt/Self-Blame	3.09	1.23	5.00	1.00	6.00
Caregiver Burden	40.34	11.69	49.00	19.00	68.00
Interdependence	55.25	9.01	50.00	23.00	73.00
<i>Termination</i>					
Shame	1.70	1.23	5.00	1.00	6.00
Guilt/Self-Blame	2.05	.93	4.00	1.00	5.00
Caregiver Burden	33.55	10.82	43.00	19.00	62.00
Interdependence	55.89	9.15	48.00	23.00	71.00

Table 3. Baseline and Termination Means for Primary Variables at Termination of CIT-S vs. Psychoeducation.

Condition	BL Shame	Term. Shame	BL Guilt/Self-Blame	Term. Guilt/Self-Blame	BL Burden	Term. Burden	BL Inter.	Term Inter.
CIT-S	2.41	1.66	3.11	1.43	39.92	31.15	55.35	55.91
Psychoed.	2.84	1.74	3.07	2.67	40.77	35.94	55.15	55.88

Table 4. Path Coefficients, Standard Errors and p-Values for Direct Effects

	$\beta$	<i>b</i>	SE
Treatment Condition to Caregiver Burden	2.058**	.619	.815
Treatment Condition to Guilt/Self-Blame	.397*	.413	.191
Treatment Condition to Shame	.224	.200	.095
Treatment Condition to Interdependence	-.109	-.103	.001

\*p < .05.

\*\*p < .001.

Table 5. Path Coefficients, Standard Errors and z-Values for Direct Effects and Indirect Effects

	$\beta$	<i>b</i>	SE
<b>Between Level</b>			
Treatment Condition to Caregiver Burden	2.252**	.630	.234
Treatment Condition to Guilt/Self-Blame	.391*	.474	.197
<b>Within Level</b>			
Guilt/Self-blame to Caregiver Burden	.345*	.403	.129
<b>Indirect Effects</b>			
Treatment Condition to Caregiver Burden via Guilt/Self-blame	.497		1.155*
Treatment Condition to Caregiver Burden via Shame	-.176		.713

\*p < .05.

\*\*p < .00

Appendix I

*Burden Assessment Scale*

Below you will find a list of things which have happened to other people because of their illness/their relative's illness. Answer the following questions based on the extent to which YOU have felt burdened by any of the following experiences during the past three months (or since your last assessment) because of your/your relative's illness. Please circle your answers.

1. Had financial problems.

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

2. Missed days at work (or school).

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

3. Found it difficult to concentrate on your activities.

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

4. Had to change your personal plans like taking a new job, or going on vacation

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

5. Cut down on leisure time.

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

6. Found the household routine was upset.

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

7. Had less time to spend with friends.

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

8. Neglected other family members' needs.

**Not at all (1)**            **A little (2)**            **Some (3)**            **A lot (4)**

9. Experienced family frictions and arguments.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

10. Experienced frictions with neighbors, friends, or relatives outside the home.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

11. Became embarrassed because of your relative's behavior.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

12. Felt guilt because you were not doing enough to help your relative.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

13. Felt guilt because you felt responsible for causing your relative's problem.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

14. Resented your relative because he/she made too many demands on you

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

15. Felt trapped by your illness/caregiving role.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

16. Were upset about how much you/your relative had changed from his/her former self

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

17. Worried about how your behavior with your relative might make the illness worse.

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

18. Worried about what the future holds for your relative

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

19. Found the stigma of the illness upsetting

**Not at all (1)            A little (2)            Some (3)            A lot (4)**

*Singlelis – Self Construal Scale*

Directions: Read each statement carefully and circle one number per question indicating the extent to which you agree or disagree with the statement. Do not circle the words.

1. If my brother or sister fails, I feel responsible  
strongly disagree    1       2       3       4       5       6       7       strongly agree
2. I have respect for the authority figures with whom I interact.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
3. It is important for me to maintain harmony within my group.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
4. Even when I strongly disagree with group members, I avoid an argument  
strongly disagree    1       2       3       4       5       6       7       strongly agree
5. I respect people who are modest about themselves.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
6. I should take into consideration my parents' advice when making education/career plans.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
7. It is important to me to respect decisions made by the group.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
8. I often have the feeling that my relationships with others are more important than my own accomplishments.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
9. My happiness depends on the happiness of those around me.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
10. I will stay in a group if they need me, even when I am not happy with the group.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
11. I will sacrifice my self-interest for the benefit of the group I am in.  
strongly disagree    1       2       3       4       5       6       7       strongly agree
12. I would offer my seat in a bus to my professor.  
strongly disagree    1       2       3       4       5       6       7       strongly agree

*Self-Conscious Emotions for Schizophrenia*

Please answer the following questions. Your responses should reflect how much you have felt about the matter over the **past three months/or since the last assessment**.

**Having a relative with schizophrenia:**

1) Is a great source of shame:

Not at all true			Somewhat true			Very True
1	2	3	4	5	6	7

2) Is something for which I feel blameworthy:

Not at all true			Somewhat true			Very True
1	2	3	4	5	6	7

## Appendix II

### **CIT-S 53, Session 8**

Husband: I guess that is true about the mental illness. It's hard. I get angry that we both have to deal with it. I think that she is probably better off with someone with six figures, I don't think I am doing a good job taking care of her. I believe that one day because of me she won't have enough money for her medicine and another that I will find her out on the street.

Therapist: Do you think that's the only way you take care of her? Financially?

Husband: No but that's what I feel guilty about. That she's not getting the best that's out there. That I can't give that to her.

Therapist: Remember last week when we talked about which of your cultural values are most important to you?

Husband: Yes.

Therapist: If I remember correctly, making a lot of money was not one of them.

Husband: Okay, that's true.

Therapist: Do you remember some of the values that he mentioned last week?

Patient: He talked about being patient and having compassion, being a good teacher, and having humility.

Therapist: What would it be like to be with someone who has unlimited finances but didn't practice compassion or patience?

Patient: I don't think I would be doing this well.

Therapist: It sounds like it's your values that make you a wonderful caregiver for your wife, not the amount of money you may or may not have.

### **CIT-S 92, Session 5**

Mother: I feel guilty because I can only help so much and I am not there to cater him. I need to go to work, like he keeps saying. We both— his brother and I— have sacrificed jobs and other things to help him. But nothing has changed and I worry it will never be enough.

Patient: Mom, listen to me: live your life and let me live mine.

Mother: What am I supposed to do?

Patient: I need to start doing the things I need to do for myself, to be alive and to do things that a lot of people do.

Therapist: Do you think there is any message you convey to your son when you sacrifice everything for him?

Mother: Uh oh. I remember from the handouts that being too involved is probably not the best thing. I need to accept that [the Patient] is an adult and let him live his life a bit. All things considered he is doing pretty well now that he is taking his medication and getting treatment. My not giving him enough independence probably conveys the message that he is really bad off, and that just isn't true. Doing everything for him stresses me out too, so I guess we all lose.

Therapist: Yes – Supporting the patient and helping him out is great but there is a fine line. It sounds like when you do too much for [the Patient] it is really stressful for the both of you. Giving him some independence while continuing to be supportive sounds like the best approach for both of you. Sounds like you have already made some movement in that direction, and as you noted, he seems to be doing much better.

### **CIT-S 92, Session 3**

Brother: I attended [the Patient's] doctor's appointment this Friday and it was a good meeting.

Patient: It was just a check-in. Just related to my medicines and how they are working. But afterwards we had lunch and talked about what we observed. It made me feel good, like we're doing this together. I was glad he could see me talk to my doctor and see that I'm taking care of myself.

Therapist: Great work on following through with your homework! It sounds like you both got something out of going to this appointment together.

Brother: It was good to hear from his doctor and see that [the Patient] is taking care of himself. It made me feel less "in the dark" and worried. I could see his doctor trusts him.

Therapist: Last week we talked about how each of you contributes to your family. Did this change the way you view your brother's contribution?

Brother: I guess it did. I think I got really used to seeing him the way he was when he first was sick and couldn't do anything on his own. When the doctor said he was doing a good job, it made me realize that he's not that way anymore. He contributes to the family by taking care of himself, taking his medication on his own and making sure he stays healthy for all of us.

### **CITS 102 Session 3**

Therapist: Tell me about your "ideal" family.

Father: I think my ideal family would be all of my family members just as they are, but we would all be living in the same place. Sometimes I feel like I'm dealing with this on my own, since me and [the Patient] are the only ones who live in Miami.

Therapist: I'm interested in what it's like for you to have so many family members so far away [in Peru]?

Father: It can be very difficult. Some days I feel very lonely. But luckily I'm able to talk with them and update them on [the Patient]. They care a lot about him, and always ask how he is doing and tell me they are praying for him. Once they had a mass dedicated to him.

Therapist: How does it feel to know they are praying for your son? That they are saying mass for him?

Father: That's special, you know, that there is that bond there. Since they haven't seen [the Patient] in so long, they could have just stopped caring about him or his sickness years ago. But they want to share the difficult things as well as positive things. I think that's one of the most important parts of being a family.

Therapist: So how does your actual family compare to your "ideal" family?

Father: I guess not considering the distance, I have my ideal family.