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**Variables Associated with Feelings of Subjective Burden in Caregivers of Persons
with a Severe and Persistent Mental Illness.**

Anne-Marie Baronet

**A thesis submitted to Graduate Studies of the
University of Ottawa as partial fulfilment of the requirements
for the degree of Doctor of Philosophy**

c Anne-Marie Baronet, Ottawa, Canada, 2001



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**This thesis is dedicated to all individuals caring for a person suffering from a severe and persistent
mental illness.**

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**Variables Associated with Feelings of Subjective Burden in Caregivers of Persons with a Severe
and Persistent Mental Illness**

Abstract

This study examined the factors associated with subjective burden in family members or friends caring for an adult with a severe and persistent mental illness. Caregivers ($N=128$) were recruited through support groups for family members or friends of a person with schizophrenia or bipolar disorder. It was hypothesized that subjective burden (Burden Assessment scale; Reinhard, Gubman, Horwitz, & Kinsky, 1994) would be predicted by coresidence status between the caregiver and the care recipient, symptomatic behaviours of the person with mental illness (Social Behavioural Assessment Schedule; Platt, Weyman, Hirsch, & Hewett, 1980), adverse effects on the caregiver's life (Burden Assessment scale; Reinhard, Gubman, Horwitz, & Kinsky, 1994), quality of the relationship between the caregiver and the person with mental illness (McMaster Family Assessment Device – General Functioning subscale; Epstein, Baldwin, & Bishop, 1983), family support (Perceived Social Support from Family scale; Procidano & Heller, 1983), sense of mastery in caregiving (Mastery scale; Pearlin & Schooler, 1978) and satisfaction received from caregiving activities (Care Work Satisfaction scale; Orbell, Hopkins, & Gillies, 1993). It was also hypothesized that subjective burden would, in turn, predict caregivers' depressive symptoms (Centre for Epidemiologic Studies Depression scale; Radloff, 1977) and caregivers' satisfaction with life (Satisfaction with Life scale; Diener, Emmons, Larsen, & Griffin, 1983). Research hypotheses were tested using standard and hierarchical multiple regression analyses. Findings showed that symptomatic behaviours of the person with mental illness and sense of mastery in caregiving activities explained 25% of the variance in subjective burden. Sense of mastery and

subjective burden explained 28% of the variance in caregivers' depressive symptoms. Subjective burden explained 15% of the variance in caregivers' satisfaction with life. Additional analyses suggested that coresidence status between the caregiver and the person with mental illness moderated the relationship between sense of mastery in caregiving and subjective burden. For caregivers maintaining separate living arrangements with the care recipient, sense of mastery had a stronger negative association with subjective burden than for caregivers residing with the care recipients. Additional analyses also suggested that sense of mastery in caregiving mediated the association between subjective burden and the following variables: quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities. In other words, the quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities predicted sense of mastery, which in turn predicted subjective burden.

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List of Abbreviations

OB: Objective burden

SB: Subjective Burden

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Subjective Burden

Variables Associated with Feelings of Subjective Burden in Caregivers of Persons with a Severe and Persistent Mental Illness.

The deinstitutionalization movement which began more than 40 years ago resulted in many families having to care for a relative with a mental illness. Early literature evaluated the impact of caregivers' behaviors on the relative with an illness. A more recent line of research has explored the impact of functional psychiatric illness on family caregivers. Early findings indicated that the impact of mental illness extended to many aspects of family life: work, leisure, income, children, family health, and relations with extended family, friends, and neighbours (Clausen & Yarrow, 1955; Grad & Sainsbury, 1968). Because the behavior of the person with an illness required that caregivers and other family members place their own needs and wishes after those of that person, the phenomenon was labelled burden. Hoenig and Hamilton (1966) distinguished between the objective and subjective dimensions of burden, a distinction that has been used with some consistency to this day. Objective burden (OB) refers to the negative effects of the illness on the household (e.g., financial hardships, missed days at work, modified personal plans, reduced leisure time, disrupted household routine, frictions with family and friends, neglect of other family members' needs) and the caregiving demands placed on family members. Subjective burden (SB) refers to the caregivers' or family members' personal appraisals of the situation and the extent to which individuals perceive they are carrying a heavy load (Maurin & Boyd, 1990).

National statistics do not include information on the prevalence of caregiving activities. Caring for a relative with a mental illness is not systematically reported to authorities and family caregivers who get in touch with the mental health system and community associations represent a subgroup of all people involved in this type of care. The National Institute of Mental Health and

the Canadian Mental Health Association estimate that 2.0% to 2.6% of the adult population suffer from a major mental illness. The tendency to favour outpatient treatment has resulted in most of these individuals residing in the community. In the United States, it is estimated that up to 65% of patients discharged from mental hospitals return to live with their families (Goldman, 1982; Lefley, 1987a). It is also estimated that about 35% to 40% of persons with severe and persistent mental illnesses live with their families on an ongoing basis (Lefley, 1987b). A recent survey of the prevalence of caregiving in Ontario, Canada indicated that approximately 15% of the adult population aged 15 to 64 provided informal care for a relative or a friend with an illness (Cochrane, Goering, & Rogers, 1997). In this survey, informal caregivers provided help because of chronic illness, old age, disability, mental retardation or mental illness. The number of caregivers residing with the care recipient (4.7%) was half of the number who did not reside with the care recipient (9.4%). Forty-one percent of caregivers reported that caring tasks interfered with their other activities. Caregivers who resided with the care recipient spent more time weekly in caregiving activities (35 hours) than those who did not reside with the care recipient (10 hours). In addition, caregiving provided in the home interfered more with caregivers' other activities.

Literature Review

In 1990, Maurin and Boyd conducted a critical review of the caregiving literature in mental illness and provided a good evaluation of the methodological problems in this field of research. Methodological issues highlighted included the inconsistent use of theoretical and operational definitions, reliability and validity issues in the measurement of burden, problems in sampling, heterogeneity of the population studied, the absence of longitudinal research designs, and the lack of simultaneous control of the various variables influencing burden. These

methodological problems accounted for some of the inconsistencies and variability in findings among studies. The purpose of the present review is to report empirical research findings about caregiver burden in severe and persistent mental illness, to discuss these findings in light of the methodological problems identified by Maurin and Boyd, and to highlight areas that need further attention in future research work.

Inclusion Criteria

Study abstracts that included the words burden and any of the following words: family, caregiver, caretaker or careprovider, were identified through a computer search in the Psych Info system, 1967 to 1999. The reference sections of these studies were also verified to ensure that no burden studies were left out. Selected studies were designed to: (1) evaluate burden (behaviors and feelings specifically associated with caregiving in mental illness) rather than distress (global picture of the caregivers' physical and mental health, in relation to current stressors not necessarily associated with mental illness) (Jones & Jones, 1994); (2) focus on family members or friends who were involved in caring activities; and (3) focus on caregivers of persons with a severe and persistent mental illness including schizophrenia- related diagnoses and other affective disorders. Studies of caregivers of persons with cognitive impairment (i.e., dementia) were not included in this review. One reason underlying this decision was to reduce the heterogeneity of the population studied with regard to their experience in caregiving. However, the large body of literature on caregivers of family members with cognitive impairment (i.e., dementia) was considered to facilitate selection of study variables and to occasionally compare the relative importance of predictor variables in caregiving for persons with these different illnesses (i.e., dementia and severe mental illness). Therefore, in this thesis, caregiving in "mental illness" refers

to severe and persistent mental illness including schizophrenia- related diagnoses and other affective disorders.

Selected studies used measures which identified the type of burden evaluated (e.g., objective, subjective, global) and when applicable, dimensions of burden (e.g., stigma, fears, worry). Studies also used measures on which psychometric properties had been reported in the published literature. Preferred evidence of validity involved demonstration of construct or criterion-related validity. Minimal evidence of validity involved the use of items taken from the research literature on caregiver burden, or the use of items taken from other burden scales with established psychometric properties. Evidence of reliability often involved level of internal consistency (e.g., Cronbach's alpha coefficient) equal to or higher than .70, as accepted in the statistical literature as an acceptable level of reliability (Spector, 1992). Preferred evidence of reliability involved, in addition to the Cronbach's alpha coefficient, test-retest or interrater coefficients. Because a small number of measurement instruments showed preferred evidence of validity and reliability, only minimal evidence of validity and reliability were required as inclusion criteria. These criteria were selected to improve the comparability of findings across studies, and to make it easier to determine whether inconsistent findings were theoretically relevant or only a result of the various conceptualizations and measures adopted by different researchers (Raveis, Siegel & Sudit, 1988).

Thirty-four studies met the above criteria and were included in the review. Although these studies were of variable scope, description of their research design and findings was limited to the extent of their contribution to the area of caregiver burden in mental illness. For example, in Greenberg, Seltzer, Krauss and Kim's (1997) study of the differential effects of sources of stress

and support on caregivers of adults with mental illness or mental retardation, only findings about caregivers in mental illness were reported.

Sample Selection and Characteristics

Respondents of the studies reviewed were mostly female caregivers (69%), and averaged 52 years of age. Most of them were White (75%) and often resided with the person suffering from mental illness (43%). Minority caregivers of the reviewed studies were Black. Caregivers usually had a high school diploma and an average family income of \$25 000. Respondents were often parents (55%) or spouses (22%) of the person with a mental illness. Studies included in this review either recruited caregivers through clients receiving services at psychiatric facilities or contacted them directly in support groups.

Research Findings

Three types of research findings were reported in the reviewed studies. Descriptive statistics presented the relative occurrence of OB and SB. Descriptive statistics also identified activities found most burdensome to caregivers. Correlations were computed between burden and different variables, as well as between OB and SB. Regression analyses identified the relationship between a specific variable and burden, controlling for the confounding effects of other variables on burden. Findings about associations between variables and burden with probabilities less than or equal to .05 were considered significant in this review. However, many studies conducted multiple tests and did not address the issue of Type I error. The issue of Type I error should be kept in mind when reading this review. Major findings of the studies, along with information about research designs, statistical analyses, sampling procedures and variables included are reported in Table 1.

Nature of Burden Experienced

Objective and subjective burden. Descriptive statistics were presented about the relative occurrence of OB and SB. Findings were difficult to interpret because of their qualitative as opposed to quantitative nature. They were also difficult to interpret because of the varied ways in which OB was measured. Gibbons, Horn, Powell and Gibbons (1984) conceptualized OB in terms of symptomatic behaviors, level of functioning of the person with mental illness and adverse effects on the household. Jones (1996; Jones & Jones, 1994; Jones, Roth & Jones, 1995) conceptualized OB in terms of both help in daily living tasks and supervision activities provided to the person with mental illness. Finally, Potasznik and Nelson (1984) and Thompson and Doll (1982) conceptualized OB in terms of adverse effects on the caregivers' lives. A tentative pattern of findings emerged from these studies: more OB was experienced as a result of the tasks related to the caregiving situation than because of the disruptive behaviors of the person with mental illness. Conversely, more SB was experienced as a result of the disruptive behaviors of the person with mental illness than because of the tasks related to the caregiving situation. Reported associations between OB and SB have ranged from .26 to .94 (Cornwall & Scott, 1996; Jones; Potasznik & Nelson; Thompson & Doll). The measurement of OB in terms of assistance, supervision and adverse effects on the caregivers' lives may have contributed to the variability in reported correlational findings.

Burdensome activities. Activities found most burdensome to caregivers were highlighted by initially selecting the activities reported as most burdensome in each study, and then identifying those activities that were most frequently reported across studies. Highest OB was reported for

providing transportation, help in money management, housework and cooking, need for constant supervision, restrictions in caregivers' personal activities and providing financial help. Highest SB was reported for issues of safety and possible violence of the person with mental illness toward self and other, excessive demands and high dependency toward caregiver, night disturbances, embarrassing behaviors, symptomatic behaviors, worries about the future, and uncooperative attitude leading to conflicts and family hardships. These findings were congruent with the pattern of results of OB being highest with daily assistance activities and SB being highest in supervision type of activities.

Variables Associated with Burden

Regression results of the studies reviewed indicate the degree to which certain variables were associated with the occurrence of burden. Because regression analysis is a stronger method for identifying relationships between variables than is correlational analysis, only regression results were interpreted and discussed in the text. Furthermore, discussion of findings is limited to replicated results (i.e., two or more studies finding similar results). Occasionally, non-replicated findings are discussed and are clearly identified in the text. For the purpose of the review, variables have been divided into five categories: socio-demographic, illness-related, caregiver support, caregiver appraisal and caregiver adaptation. Nineteen out of the 34 studies reviewed presented regression results.

Socio-demographic variables. The associations of caregiver burden with the following socio-demographic variables were studied: caregivers' age, gender, ethnicity, education, family income, kinship with the person with mental illness, residing with the person with mental illness and gender of the person with mental illness. Relationships were found between burden and

caregivers' age, ethnicity and residing with the person with mental illness. No relationship was established between burden and caregivers' gender, education, family income, kinship with the person with mental illness and gender of the person with mental illness.

Eleven studies evaluated the relationships between caregivers' age and burden. Caregivers' young age was associated with increased stigma (SB) and fears (SB) for their own safety and the safety of the person with mental illness (Greenberg, Kim, & Greenley, 1997; Pickett, Greenley, & Greenberg, 1995). It was not associated with worry (SB) (Greenberg, Kim et al. Pickett, Greenley et al.), or with global SB (Greenberg, Kim et al.; Noh & Avison, 1988; Seltzer, Greenberg, Krauss, & Hong, 1997; Solomon & Draine, 1995; Webb et al., 1998). Caregivers' young age was also associated with high levels of global burden (i.e., OB and SB combined; Horwitz & Reinhard, 1995; Stueve, Vine, & Struening, 1997).

Six studies evaluated the relationships between ethnicity and burden. Being White was associated with increased global burden (Horwitz & Reinhard; Stueve et al.). No associations were found between ethnicity and SB (Jones et al., 1995; Solomon & Draine; Song, Biegel, & Milligan, 1997).

Six studies evaluated the relationships between residing with the person with mental illness and burden. Replicated findings showed that residing with the person with mental illness was associated with increased OB (Jones et al.; Pickett, Greenley et al.; Tessler & Gamache, 1994), increased SB (Seltzer et al.; Solomon & Draine), but not associated with worry (Pickett, Greenley et al.; Tessler & Gamache). This suggests that caregivers who did not reside with the person they were caring for still worried as much about them.

Eleven studies evaluated the relationships between burden and caregivers' gender. None

of them found association with OB (Jones et al., 1995; Pickett, Greenley et al., 1995; Reinhard, 1994), worry (SB) (Greenberg, Kim et al., 1997; Pickett, Greenley et al.), fears (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.), stigma (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.), global SB (Cook, Lefley, Pickett, & Cohler, 1994; Greenberg, Kim et al.; Jones et al.; Noh & Avison, 1988; Solomon & Draine, 1995; Song et al., 1997; Webb et al., 1998), or global burden (Horwitz & Reinhard, 1995; Reinhard; Stueve et al., 1997).

Seven studies evaluated the relationships between burden and caregivers' number of years of formal education. They did not find any association between education and OB (Reinhard), worry (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.), fears (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.), stigma (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.), global SB (Greenberg, Kim et al.; Noh & Avison; Solomon & Draine), or global burden (Reinhard; Horwitz & Reinhard).

Five studies included family income in their research design. None of them found an association between income and OB (Clark, 1994; Reinhard), SB (Noh & Avison; Solomon & Draine), or global burden (Reinhard; Stueve et al.).

Four studies evaluated the relationships between kinship with the person with mental illness and burden. Replicated findings showed that being a parent or a primary kin of the person with mental illness was not associated with global burden (Horwitz & Reinhard; Stueve et al.).

Finally, four out of six studies that included gender of the person with mental illness as a possible factor influencing burden found that it was not associated with OB (Clark; Pickett, Greenley et al.), worry (Greenberg, Kim et al.; Pickett, Greenley et al.), stigma (Greenberg, Kim et al.; Pickett, Greenley et al.), fears (Greenberg, Kim et al.; Pickett, Greenley et al.) or global SB

(Greenberg, Kim et al.; Seltzer et al., 1997).

Illness-related variables. The associations of caregiver burden with the following illness-related variables were studied: symptomatic behaviors of the person with mental illness, level of involvement in caregiving activities and diagnosis of the person with mental illness. Caregiver burden was positively related to the presence of symptomatic behaviors and involvement in caregiving activities, but was not related to diagnosis of the person with mental illness.

Thirteen of the fourteen studies evaluating the relationships between caregiver burden and symptomatic behaviors found associations between both variables. Symptomatic behaviors were positively associated with OB (Biegel, Milligan, Putnam, & Song, 1994; Clark, 1994; Pickett, Greenley et al., 1995; Potasznik & Nelson, 1984; Reinhard, 1994), worry (SB) (Greenberg, Kim et al., 1997; Pickett et al.), stigma (SB) (Biegel et al.; Greenberg, Kim et al.; Pickett, Greenley et al.), fears (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.), global SB (Greenberg, Kim et al.; Noh & Avison, 1988; Potasznik & Nelson; Song et al., 1997; Webb et al., 1998), and global burden (Biegel et al.; Bulger, Wandersman, & Goldman, 1993; Reinhard; Stueve et al.; 1997). Greenberg, Seltzer and Greenley (1997) did not find a relationship between symptomatic behaviors and SB, but symptomatic behaviors had been measured 36 months prior to measuring SB. Among all factors associated with caregiver burden, symptomatic behaviors presented the strongest and most consistent associations.

Four studies evaluated the relationships between involvement in caregiving activities and caregiver burden. Replicated findings showed that it was positively associated with worry (SB) (Greenberg, Kim et al.; Pickett, Greenley et al.) and global burden (Horwitz & Reinhard, 1995; Stueve et al.). Amount of care was not associated with fear (SB) or stigma (SB) (Greenberg,

Kim et al.; Pickett, Greenley et al.).

Five studies evaluated the relationships between diagnosis and caregiver burden (Greenberg, Kim et al., 1997; Horwitz & Reinhard, 1995; Noh & Avison, 1988; Solomon & Draine, 1995; Webb et al., 1998). Although the diagnostic strategy was rarely described, replicated findings showed that diagnosis was not related to global SB (Noh & Avison; Solomon & Draine; Webb et al.). It is of interest that diagnosis, which is related to symptomatology, is not related to caregiver SB when symptomatic behaviors present such strong relationships with burden. Symptomatic behaviors which yielded highest levels of reported SB in caregivers (e.g., issues of safety and possible violence of the person with mental illness toward self and others, excessive demands, high dependency toward the caregiver) are not exclusively related to specific diagnoses, but usually appear in periods of crisis and exacerbation of various severe psychiatric illnesses. People suffering from a mental illness that were included in two of the three studies that found no association between diagnosis and SB were living in the community as opposed to being recently admitted to a psychiatric setting. The stability of these persons' conditions in terms of psychiatric symptomatology may therefore have confounded the relationship between diagnosis and SB.

Caregiver support variables. The associations between burden and the following sources of support were evaluated: social, professional, self-help and family, as well as with the quality of the relationship with the person suffering from a mental illness. Nine studies evaluated the associations between caregiver burden and the following sources of support: social, professional and self-help group. Social support was not associated with OB (Biegel et al., 1994; Potasznik & Nelson, 1984). There was also no relationship between social support and SB when social

support was evaluated in terms of the size of the social network (Greenberg, Seltzer et al., 1997; Potasznik & Nelson), satisfaction with social support (Potasznik & Nelson; Song et al., 1997), and density of social network (Potasznik & Nelson). With the exception of Stueve et al. (1997), studies which evaluated the relationship between perceived quality of social support and SB found no association between the two variables (Magliano et al., 1998; Noh & Avison, 1988; Song et al.; Webb et al., 1998). Studies evaluating the relationship between instrumental help and SB yielded mixed findings. Magliano et al. and Stueve et al. found no relationship between the two variables, whereas Solomon and Draine (1995) found that instrumental help was associated with lower feelings of SB. Differences in findings could not be explained by differences in participant caregivers. Two studies evaluated the relationship between social support and global burden and yielded mixed findings. Stueve et al. found that quality of social network was associated with global burden, whereas Biegel et al. found no relationship between social support and global burden.

The lack of association between social support and SB in caregivers for people with a severe mental illness contrasts sharply with the strong association between social support and SB reported in the caregiving literature for older people with a cognitive impairment. An important difference between the two caregiving situations is the quality of support services available to caregivers. Homecare services are more accessible for caregivers of older persons with a cognitive impairment than they are for caregivers in severe mental illness. As there is less stigma associated with dementia than with severe mental illness, community service providers are more willing to offer home support services to older people with a cognitive impairment. Support groups have been in place for a longer time for caregivers of older people than for caregivers of

people with a severe mental illness. They typically have better funding and more volunteers. In addition, day care and respite care facilities for people with dementia are usually structured and well organized. In contrast, respite care beds are almost non-existent for people with severe mental illness, and day care activities usually consist of a drop-in centre where people with severe mental illness go to drink coffee and watch television. Few structured, intellectually stimulating activities are planned in these drop-in centres, and attendance is usually sporadic. It is possible that the superior quality of support services offered to caregivers for older people with a cognitive impairment contribute to the differential impact of social support on SB between the two populations of caregivers.

Three studies evaluating the relationship between membership in a support group and burden yielded mixed findings. Greenberg, Seltzer et al. (1997) found that being a member of a support group was negatively associated with SB, whereas Solomon and Draine (1995) found that it was not associated with SB. Non-replicated findings by Potasznik and Nelson (1984) suggest that perceived quality of support received from other members of the support group was negatively associated with OB, but not associated with SB. It should be noted that the length of time the caregiver was involved in the support group and attendance to meetings were not evaluated in these studies. Three studies evaluated the relationships between aspects of professional support and caregiver burden. Replicated findings showed that perceived sufficiency of professional support (Biegel et al., 1994) and receiving practical advice in managing symptomatic behaviors (Reinhard, 1994) were negatively associated with OB. These two forms of professional support were not associated with global burden. Receiving practical advice was one aspect of Reinhard's professional support measure. When both instrumental and affective

dimensions of support obtained from professionals were combined, professional support was not related to OB. A non-replicated finding (Magliano et al., 1998) suggests that professional support may not be related to SB. Non replicated findings have shown that high levels of support from family members were associated with lower levels of stigma (Biegel et al.), and that the amount of time the caregiver's spouse spent with the ill relative was negatively associated with SB (Potasznik & Nelson). Although some of these findings were not replicated, it appears that support related to improving the caregiver's ability in dealing with the ill relative (sources of support being professional or support group) was negatively related to OB, but not related to SB or global burden. Conversely, social and familial sources of support were more likely to be related to SB or global burden.

Two studies evaluated the association between SB and the quality of the relationship between the caregiver and the person with a mental illness. Because these studies focused on different aspects of the relationship, the findings cannot be compared. High levels of intimacy between the caregiver and the client were associated with low SB (Bulger et al., 1993) whereas high levels of conflicts were associated with high SB (Bulger et al.; Potasznik & Nelson, 1984).

Overall, caregiver support variables which were associated with SB were more likely to involve family relationships, whereas those support variables which yielded inconsistent or no associations with SB were more likely to involve relationships with individuals outside the family environment. These non-replicated associations between family relationship variables and SB suggest the importance of the family environment in the caregiver's appraisal of the situation. It is surprising that few studies have included family support variables in their evaluation of burden. Because caregiving activities tend to isolate caregivers from the external world, the family

environment may take on increasing importance for them. Furthermore, the quality of the relationship between the caregiver and the person with mental illness, which is omnipresent in caregiving activities, is likely to influence the context in which caregiving activities are provided and appraised by the caregiver. Family support, including the quality of the relationship between the caregiver and the care recipient, merits further attention from researchers.

Caregiver appraisal variables. Replicated findings showed that sense of mastery was negatively associated with SB (Noh & Avison, 1988; Solomon & Draine, 1995). Non replicated findings about related constructs yielded similar results: sense of self-efficacy and satisfaction with coping responses were also negatively associated with SB (Solomon & Draine). Non replicated findings also showed that caregivers who experienced a sense of gratification from their caregiving duties had lower levels of SB than those who did not (Bulger et al., 1993).

The lack of attention given to positive appraisal variables in the caregiver burden literature in mental illness is surprising. The experience of SB in caring for a person with mental illness does not prevent caregivers from also perceiving other aspects of caregiving in a positive way. In addition, the ability to appraise aspects of caregiving positively may influence levels of burden experienced by the caregiver. In the general population, the ability to perceive a situation positively was associated with greater levels of well-being and lower levels of distress (Reker, Peacock & Wong, 1987). Similar findings were also reported in studies of caregiving for older persons with cognitive impairment (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Kramer, 1997; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Noonan, Tennstedt, & Rebelsky, 1996), for adults with mental retardation (Smith, 1996) and for a handicapped child (Bristol, 1987). Studies using a LISREL analysis, which suggests direction of relationships

between variables, found that satisfaction in caregiving influenced SB (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Lawton, Rajagopal, Brody, & Kleban, 1992). The ability to appraise caregiving positively was most often neglected in prior research in caregiving in mental illness. The current study was designed to address this need.

Caregiver adaptation variables. Replicated findings showed that caregivers' overall rating of their own health was not associated with SB (Greenberg, Kim et al., 1997; Seltzer et al., 1997; Song et al., 1997). Non replicated correlational findings showed that caregivers who presented higher levels of depressive symptoms also experienced higher levels of SB (Pickett, Vraniak, Cook, & Cohler, 1993). However, because of the cross sectional design of the study and type of statistical analyses used, it was not clear whether the presence of SB led caregivers to present depressive symptoms, or the presence of depressive symptoms led caregivers to perceive caregiving as being more burdensome.

Other studies investigated the relationship between caregiver burden in mental illness and adaptation outcomes. In these studies, caregiver burden was entered in regression equations as a predictor of the outcome variable. OB (Coyne et al., 1987), SB (Coyne et al.; Noh & Turner, 1987; St-Onge & Lavoie, 1997) and global burden (Szmukler et al., 1996) were positively associated with measures of psychological distress. OB (Greenberg, Greenley & Brown, 1997) and SB (Greenberg, Greenley et al.; Song et al., 1997) were also positively associated with depressive symptomatology in caregivers.

Physical and psychological health have been used repeatedly as adaptation outcomes in the stress and coping literature, and in the literature about caregiving in other illnesses. Depressive symptoms were found to be associated with SB in the caregiving literature for older persons with

cognitive impairment (Lawton et al., 1991; Lawton et al., 1992; Talkington-Boyer & Snyder, 1994; Rankin, Haut, & Keefover, 1992). Research findings in the caregiving literature for persons with cognitive impairment (i.e., dementia) also showed that SB was associated with the experience of positive affect (Lawton et al., 1989; Lawton et al., 1991; Lawton et al., 1992). Of the studies mentioned above, those using a LISREL analysis indicated relationships from SB to both depressive symptoms and positive affect in caregivers (Lawton et al., 1991; Lawton et al., 1992).

The literature in caregiving for older persons with cognitive impairment is pertinent, especially with regard to positive appraisal and adaptation outcome variables. Although some findings about caregiving for people with cognitive impairment may also have relevance for caregivers in mental illness, the reader should keep in mind the differences between these illnesses and associated implications for caregivers' experience of SB. For example, severe mental illness involves cycles of exacerbation and remission of symptoms, as opposed to dementia which involves a steady decline in the cognitive capacities of the individual. Well-being of the person with mental illness is therefore less predictable, which may make caregiving in mental illness a more stressful experience. Another difference characterizing caregiving in these two illnesses involves the blame that mental health professionals have placed, especially in the past years, on families of persons with severe mental illness for their relatives' condition. As a result, some caregivers of persons with mental illness feel guilty and are afraid that their behaviors may have caused the person's illness (Lefley, 1996). Fortunately, there is less stigma associated with dementia and mental health professionals have not adopted a similar judgmental attitude towards caregivers.

A third difference involves the onset of the illness in the life cycle of the person with mental illness. Severe mental illness develops in early adulthood at a time where the person should have acquired enough autonomy to initiate independent living. The illness brings a decrease in autonomy, a process that is totally opposite to what is expected from maturation. A degenerative illness usually develops later in the life cycle. Although a decrease in autonomy is expected in older age, the dementia illness usually accelerates this process (i.e., earlier onset and more severe and rapid deterioration). The discrepancy between social role expectations and actual levels of functioning of the care recipient is likely to affect the experience of caregiving in family members and to increase caregivers' SB. Furthermore, when the caregiver in severe mental illness is a spouse, the onset of the illness in the care recipient happens at a time when the caregiver is usually coping with multiple roles including being a parent of young children, establishing a career, being the main financial provider of the family etc. These competing demands on the caregiver's time and attention may also contribute to increase SB. In addition, for spouse caregivers in severe mental illness, withdrawing from the caregiving role when the demands of caregiving exceed caregivers' abilities may mean the end of the marital relationship, which may contribute to increase feelings of guilt and failure in caregivers. In contrast, spouse caregivers of older people with a cognitive impairment will usually consider the end of caregiving activities and institutionalization as a normal transition in the caring process and will not relate this transition to the quality of the marital relationship.

Another factor which may contribute to SB involves the length of time spouse caregivers expect to be involved in caregiving activities. For spouse caregivers in dementia, the caregiving career is expected to last for a limited period of time, as the caregiver usually outlives the care

recipient. However, caregivers in severe mental illness tend to face an unlimited career, as the care recipient usually lives as long as the caregiver or even outlives the caregiver in the case of parents caring for an adult child. As a result, parent caregivers often deal with the additional worry of who will take care of their disabled adult child when they pass away.

Finally, caregivers are more likely to experience SB when they believe that behavior problems are the result of the care recipient's lack of cooperation and negative attitude, than if they believe the problems are the result of mental illness (Greenberg, Kim et al., 1997). Because of the later onset of dementia in the life cycle, it is easier for the caregiver to refer to a time when his or her relationship with the care recipient was not affected by the illness, and to identify the problematic behaviors that accompanied the development of the illness. The earlier onset of severe mental illness may make it more difficult for caregivers to relate problematic behaviors to the illness, and may contribute to increase SB.

Other differences between dementia and severe mental illness may affect the caregivers' experience. No research has been published to determine if factors that influence the experience of caregiving for persons with cognitive impairment are also relevant to caregiving for persons with severe mental illness.

The lack of theoretical models explaining the experience of caregiving in mental illness may have contributed to the absence of adaptation outcome variables in prior studies. Researchers should attempt to replicate findings on the relationship between SB and depressive symptoms, and should attempt to evaluate the relationship between burden and positive forms of adaptation outcomes such as satisfaction with life. Researchers should also conceptualize variables related to caregiver burden in a theoretical framework to facilitate understanding of the

relationships between the different variables and to increase the likelihood that important variables in caregiving are represented in study designs.

Summary of the Variables Associated with Burden

Table 2 presents a summary of the relationships between variables and the different dimensions of burden. Regression study findings that were replicated on at least one occasion are represented in this summary table. Relationships between variables and burden dimensions are shown as positive, negative or no relationship. When different replicated results were obtained about the relationship between a variable and a burden dimension, the overall effect is shown as mixed.

With the exception of isolated associations found between age of caregiver, ethnicity, coresidence status between the caregiver and the person with mental illness and some dimensions of burden, socio-demographic variables were not associated with caregiver burden. By contrast, symptomatic behaviors of the person with mental illness showed the strongest and most consistent relationships with the different dimensions of caregiver burden. Involvement in caregiving, another illness-related variable, showed associations with some dimensions of burden, whereas diagnosis was not related to SB. Caregiver support variables, especially forms of support provided through social network and support group, presented mixed associations with caregiver burden. It is possible that the impact of social support and support obtained through a support group on caregiver burden might be more a result of the effect of these variables on the relationship between an independent variable and caregiver burden (e.g., symptomatic behaviors and SB) than a result of a direct relationship between these forms of support and burden. Finally, little attention was given to the impact of caregiver appraisal and adaptation variables on caregiver

burden. Caregiver' sense of mastery was negatively related to SB whereas no relationship was found between caregiver health and SB.

Burden Over Time

Seven studies used longitudinal designs and evaluated caregiver burden over periods of time ranging from three months to three years. Coresidence status, symptomatic behaviors and social support were predictor variables included in these longitudinal designs. Replicated findings showed that OB and SB were relatively stable over time (Jones, 1996; Tessler & Gamache, 1994; Test & Stein, 1980). Seltzer et al. (1997) and Greenberg, Seltzer et al. (1997) found that burden at time 1 was a strong predictor of burden three years later. An increase in symptomatology also predicted the end of the coresidence status between the caregiver and the person with mental illness (Seltzer et al.), which resulted in a decrease in SB (Greenberg, Seltzer et al.; Seltzer et al.). Herz, Endicott and Spitzer (1976) found that a brief hospitalization of the person with mental illness was associated with a decrease in burden. Tessler and Gamache found that coresidence status when the person with mental illness was not receiving continuity of care resulted in increased burden. An increase in symptomatic behaviors was associated with an increase in caregiver burden (Cornwall & Scott, 1996; Herz et al.; Jones, 1996). Finally, Greenberg, Seltzer et al. found that social support, especially being a member of a support group and having close friends who also cared for a person with mental illness predicted burden three years later.

Implications of the Review Findings

Problematic areas highlighted by the present literature review on caregiver burden in mental illness include the lack of attention given to family resources, positive appraisal and adaptation outcome variables, as well as the absence of a theoretical framework for caregiving in

mental illness.

The lack of attention given to family resource variables in the SB equation is an important limitation. Because caregiving activities tend to isolate the caregiver from the external world, family life often takes on increasing importance. Non replicated findings have shown that SB was related to family support and to the quality of the relationship with the ill relative. In a literature review of caregiving for older persons with cognitive impairment, Kramer (1997) found that family environment variables were related to positive and negative appraisal of the caregiving situation. SB in caregiving for older persons with cognitive impairment was also related to the quality of the relationship with the older person (Cantor, 1983; Draper, Poulos, Poulos, & Ehrlich, 1996; Horowitz & Shindleman, 1983; Poulshock & Deimling, 1984). The quality of the relationship between the caregiver and the person with mental illness is important because most of the caregiving activities are provided through this relationship. It is omnipresent in caregiving and influences the atmosphere and the context in which caring activities are provided. Therefore, researchers should attempt to replicate initial findings about family support and to determine whether or not findings about the quality of the relationship between the caregiver and older persons with cognitive impairment are also characteristic of caregiving in mental illness. In a recent review of the research literature about families of persons with a psychiatric illness, Rose (1996) highlighted the absence of information about the quality of the relationship with the person with mental illness and the need to investigate its impact on caregivers' appraisal of the caregiving situation.

The lack of attention to caregiver positive appraisal variables in caregivers' experience of SB is also an important limitation of the caregiving literature in mental illness. Because SB, a

negative appraisal variable, was the dependant variable in the studies reviewed, most authors did not attempt to evaluate other forms of appraisal and their possible relationship to SB. Studies in caregiving for older persons with cognitive impairment included other caregiver appraisal variables in their research designs, and found that SB was negatively associated with the perception of gain in caregiving (Farran et al., 1991), caregiver satisfaction (Lawton et al., 1991; Lawton et al., 1992; Talkington-Boyer & Snyder, 1994) and caregiver mastery and caregiver's confidence in self (Talkington-Boyer & Snyder). Again, future research should attempt to determine whether or not these relationships in caregiving for the older person with cognitive impairment are also characteristic of caregiving in mental illness.

A third limitation involves the lack of attention given to adaptation outcome variables and their relationship to SB. Studies showed that SB in caregiving in mental illness explained variability in the caregiver's level of psychological distress (Coyne et al.; Noh & Turner, 1987; St-Onge & Lavoie, 1997), and in the caregiver's depressive symptomatology (Greenberg, Greenley et al., 1997; Song et al., 1997). The relationship between SB in caregiving in mental illness and a measure of positive adaptation outcome in the caregiver was not studied. In caregiving for older persons with cognitive impairment, SB predicted the experience of positive affect (Lawton et al., 1989; Lawton et al., 1991; Lawton et al., 1992). Future research is required to replicate findings about the impact of SB on depressive symptoms in caregivers of persons with mental illness, and to verify whether or not SB also explain variability in positive adaptation outcomes.

Another important limitation is the lack of theoretical foundation in studies of caregiving in mental illness. Most studies reviewed were exploratory in nature and did not attempt to test specific models of caregiver burden. However, many of them were implicitly based on a stress,

coping and adaptation framework, which suggests that caregiver burden is predicted by the presence of the illness and the resulting caregiving activities (the major stressors), as well as the presence of physical, psychological and environmental resources of the caregiver. Review findings have shown the validity of conceptualizing caregiver burden in a stress, coping and adaptation framework, by highlighting relationships between stressors, resources, adaptation outcomes and SB. Grounding future research work in a theoretical framework will also guide researchers in making appropriate assumptions about the relationships between different variables and SB.

Present Study

This study was designed to increase understanding of SB by addressing the most important limitations mentioned above. It was designed to evaluate the relationships between different variables and SB within a stress, coping and adaptation theoretical framework. Its purpose was to increase knowledge about the associations between coresidence status between the caregiver and the person with mental illness, caregiver stressors (i.e., symptomatic behaviors of the person with mental illness and adverse effects on the caregiver's life), caregiver family resources (i.e., quality of the relationship between the caregiver and the person with mental illness and family support), positive appraisal of caregiving (i.e., satisfaction received from caregiving activities and sense of mastery in caregiving activities), caregiver adaptation outcomes (i.e., caregivers' satisfaction with life and depressive symptoms), and SB.

Research in caregiving for people with a mental illness and for people with other illnesses suggests that coresidence status between the caregiver and the person with mental illness, stressors in caregiving, caregivers' family resources and positive appraisal of caregiving predict SB in caregivers, which in turn predicts adaptation outcomes.

Because the study was designed to clarify the relationships between specific variables and SB rather than to create a complete model explaining caregivers' experience of SB, the variables selected for the study were not expected to be a complete representation of the category in which they were included. For example, quality of the relationship between the caregiver and the person with mental illness and family support were not intended to completely represent all forms of family resources. Variables were also selected for their possible contribution to SB but not to other adaptation outcomes. For example, research findings have shown that caregivers' health

predicted caregivers' depressive symptoms, but did not predict caregivers' SB. Therefore, caregivers' health was not included in the present study. Also, for reasons of feasibility and scope of the study, not all variables relevant to SB were included. For example, the absence of social support or coping skills in the present study does not mean that these variables were considered unimportant to caregiver' SB.

The variables included in the study were limited to (1) those that were related to SB in the research literature in caregiving in severe mental illness (i.e., coresidence status, symptomatic behaviors, sense of mastery and depressive symptoms in caregivers), (2) specific variables on which findings had not been replicated in caregiving in severe mental illness (i.e., adverse effects in the caregiver's life, quality of the relationship between the caregiver and the care recipient and family support), and (3) specific variables that were related to SB in caregivers in other illnesses (i.e., satisfaction received from caregiving activities and caregivers' satisfaction with life). Testing of the relationships between SB and variables on which findings have not been replicated in caregiving in severe mental illness and those characterizing caregiving in other illnesses is the original contribution of this thesis to the present field of research.

Variables Included in the Study

Caregiver Stressors

Symptomatic behaviors of the person with mental illness. Symptomatic behaviors of the person with mental illness constitute a large part of the stressors the caregiver faces when interacting with the person with a mental illness. The conceptual definition of caregiver burden requires that the stressors considered in the equation be directly related to the care recipient's mental illness and to caregiving activities. In this regard, the symptomatic behaviors variable is an

appropriate choice. Furthermore, review findings have demonstrated that of all variables, symptomatic behaviors of the person with mental illness showed the strongest association with caregiver burden.

Adverse effects in the caregiver's life. The presence of adverse effects on the caregiver's life as a result of the care recipient's mental illness is generally referred to as one aspect of OB in the burden literature. Review findings have shown significant correlations between adverse effects and SB (Potasznik & Nelson, 1984; Thompson & Doll, 1982), but the adverse effects variable was not included in the regression equation for SB. Adverse effects on the caregiver's life were included in the present study in order to determine if they contributed to explain variability in SB. Whereas symptomatic behaviors of the person with mental illness are mostly related to the illness, the adverse effects on the caregiver's life (e.g., loss in areas of social life, leisure time, work) are more a function of involvement in caregiving activities.

Caregiver Family Resources

Quality of the relationship between the caregiver and the person with mental illness. The quality of the relationship between the caregiver and the person with mental illness was selected because of its omnipresence in caring activities, its importance in influencing the atmosphere in which caring is provided, and its known association with SB with other client groups (i.e., persons suffering from dementia). Non replicated findings have shown significant associations between SB and some aspects of the relationship between the caregiver and the person with mental illness (i.e., intimacy and conflicts).

Family support. Because caregiving activities usually result in caregivers having a limited social network and reduced involvement in social activities, the family may take on increasing

importance for them. Unfortunately, family support has been ignored in most caregiver burden studies in mental illness. Again, non replicated findings have shown a significant association between SB and one aspect of family support: the amount of time the caregiver' spouse spent with the adult child with severe mental illness.

Caregiver Positive Appraisal

Satisfaction received from caregiving activities. Because caring for a person with mental illness is an activity that impacts on all aspects of one's life, it was expected that caregivers' ability to perceive caregiving in a positive way would reduce their feelings of SB. Negative associations have been reported in the caregiving literature for older persons with cognitive impairments between the experience of SB and positive appraisal of the caregiving situation. Non replicated findings have shown a positive association between SB in mental illness and one related construct: gratification.

Sense of mastery in caregiving. Sense of mastery was also included as a positive appraisal variable. In the present study, sense of mastery refers to the sense of control, efficacy and ability to manage problems encountered in the context of caregiving. It also refers to the sense that through their caring activities, the caregiver can make a difference for the person with mental illness. Sense of mastery in caregiving was expected to be negatively related to caregivers' experience of SB. Replicated findings have shown a negative association between caregivers' sense of mastery and SB in caregiving for people with a severe mental illness.

Subjective Burden

Caregiver SB is a dependent variable in the study. SB was placed by itself in the Caregiver Burden model because (1) it differed from other forms of appraisal evaluated in the

study by its negative emphasis and because (2) it was the target variable of the present study.

Caregiver Adaptation Outcomes

Caregivers' depressive symptoms. Depressive symptoms are one negative adaptation outcome that is commonly found in individuals facing various life stressors and hardships. Studies of caregiving for persons with mental illness and for older persons with cognitive impairment found that SB explained variability in caregivers' depressive symptoms. It was also a dependent variable in the study, and was regressed on all predictor variables including SB.

Caregivers' satisfaction with life. Satisfaction with life is the other variable included in the adaptation outcomes of the Caregiver Burden model. Traditionally, adaptation outcomes were evaluated in terms of psychological dysfunctions and maladaptation, and little attention was given to positive outcomes of adaptation. In recent years, studies of SB in caregiving for older persons with cognitive impairment included positive adaptation outcomes, and found that SB was negatively associated with the experience of positive affect. The present study was designed to investigate whether the associations found between SB and positive outcomes of adaptation in caregiving for older persons with cognitive impairment would also be found with a population of caregivers for persons with mental illness. Satisfaction with life was also a dependent variable in the study, and was regressed on all predictor variables including SB.

Socio-Demographic Variables

With the exception of the coresidence status between the caregiver and the person with mental illness, the research literature suggests that socio-demographic variables were not associated with SB. Therefore, only the coresidence status (i.e., whether the caregiver resided with the person with mental illness) was included in the study. Data collected on other socio-

demographic variables (i.e., caregivers' age, caregivers' gender, caregivers' ethnicity, caregivers' level of education, family income and kinship with the ill relative) were used to provide information about participants in the present study. Again, because the study was designed to clarify relationships between variables and SB and not to create a complete model explaining the experience of SB in caregivers, socio-demographic variables which predicted outcome variables other than SB (i.e., caregivers' health predicted caregivers' depressive symptoms) were not included in the study.

Research Hypotheses

The study was designed to test the following research hypotheses generated from the review of the literature and the caregiver burden theoretical framework presented previously:

Research Hypothesis 1

It was hypothesized that maintaining separate living arrangements with the care recipient, a low occurrence of symptomatic behaviors in the person with mental illness, a low occurrence of adverse effects on the caregiver's life, a good relationship between the caregiver and the person with mental illness, good family support, a high sense of mastery and high levels of satisfaction received from caregiving activities would predict low levels of SB in caregivers.

Research Hypothesis 2

It was hypothesized that low SB would predict low levels of depressive symptoms in caregivers. Therefore, a significant proportion of the variance in depressive symptoms would be explained by SB, while controlling for the possible contribution of the other variables in the model (i.e., coresidence status between the caregiver and the person with a mental illness, symptomatic behaviors in the person with mental illness, adverse effects on the caregiver's life, quality of the

relationship between the caregiver and the person with mental illness, family support, sense of mastery and satisfaction received from caregiving activities).

Research Hypothesis 3

It was hypothesized that low SB would predict high levels of satisfaction with life in caregivers. Therefore, a significant proportion of the variance in satisfaction with life would be explained by SB, while controlling for the possible contribution of the other variables in the model (i.e., coresidence status between the caregiver and the person with a mental illness, symptomatic behaviors in the person with mental illness, adverse effects on the caregiver's life, quality of the relationship between the caregiver and the person with mental illness, family support, sense of mastery and satisfaction received from caregiving activities).

Method

Participants

Participants in the study were 128 family members (or close friends) most involved in caring for the person with severe mental illness. They did not provide care in exchange for financial compensation (paid work). Recipients of the care activities were functionally impaired adults with periodic needs for crisis stabilization and hospitalization and with ongoing needs for outpatient care and long-term rehabilitation. Their diagnoses included schizophrenia, bipolar disorder and depression with the periodic presence of psychotic symptoms. Caregivers for older persons with a cognitive impairment (i.e., dementia) were not included in this study. Caregivers were recruited from nine support and psycho-educational groups for family members or close friends of a person with a schizophrenia illness or a bipolar disorder. These support and psycho-educational groups were conducted in Edmonton, Alberta.

The required number of participants was determined by the desired power level, the number of independent variables, the expected effect size of the different predictor variables and the probability of making a Type I error. Because a power level of .80 or more is generally considered adequate for detecting a given effect (Gravetter & Wallnau, 1985), this power level was selected for the present study. An alpha level of .05 was also selected. The average effect size reported in the research literature for the impact of the different variables on SB was reviewed. The symptomatic and disruptive behaviors of the person with mental illness accounted for a minimum of 15% of the variance in SB. It was expected that the quality of the relationship between the caregiver and the person with mental illness would explain an additional 15% of the variance in SB. This estimate was based on two studies which evaluated the effect size of aspects

of the relationship with the care recipient on SB, after having identified the proportion of variance explained by symptomatic behaviors (Bulger et al., 1993; Greenberg et al., 1993). Studies which evaluated the effects of caregiver satisfaction and sense of mastery on SB (Bulger et al., 1993; Smith, 1996; Talkington-Boyer, 1994) showed an effect size between 10% and 15% (12.5% was used in the calculations). Studies which evaluated the effects of SB on adaptation outcomes (Haley, Levine, Brown, & Bartolucci, 1987; Kramer, 1993; Rankin et al., 1992; Song et al., 1997) showed effect sizes ranging from 2% to 21% (11.5% was used in the calculations). Given the number of independent variables included in regression analyses (eight), a lambda value of 15.1 obtained from Cohen's (1988) power tables was used. The following formula was used to calculate the number of research participants required to obtain a power level of .80 in the statistical analyses:

$$N = \frac{\text{lambda} (1 - R^2)}{R^2 + w} = \frac{15.1 (1 - .115)}{(.115) + 8} = 124$$

Power calculations indicated that 124 participants were required in the study.

Measures

Symptomatic Behaviors of the Person with Mental Illness

Symptomatic behaviors of the person with mental illness were assessed by a modified version of a subscale of the Social Behavioral Assessment Schedule (SBAS) (Platt, Weyman, Hirsch, & Hewett, 1980). The 22-item SBAS subscale measures the occurrence of 22 "behaviors" that are typical of severe mental illness: misery, withdrawal, slowness, forgetfulness, underactivity, overdependence, indecisiveness, worrying, fearfulness, obsessions, odd ideas, overactivity, unpredictability, irritability, rudeness, violence, parasuicide, offensive behavior,

heavy drinking, self-neglect, complaints about bodily aches and pain, and non-compliance with medication. A 23rd "behavior", disturbed sleeping habits, was added to the scale, because it was highlighted in the literature review as a symptom associated with SB. Quotation marks are placed around the word "behavior" because some items refer to memory, mood and thought contents. However, these items are measured in terms of observable actions by the person with mental illness, and therefore are referred to as "behaviors". The questionnaire was designed to be completed through a semi-structured interview, where the researcher asked specific questions (examples of the symptomatic behavior at varied degree of severity) in order to rate it on a three point scale. In the present study, caregivers were asked to rate the severity of these symptomatic behaviors in a self-report format, using as anchors for rating severity of the symptomatic behavior the same examples provided in the initial version. Symptomatic behaviors were also rated on a three-point scale, ranging from 0 (behavior absent or minimal) to 2 (behavior highly problematic in frequency and severity).

The internal consistency of the initial version of the SBAS disruptive behavior subscale is excellent (.96) (Platt et al., 1980). Evidence of concurrent validity was shown by high correlations between the SBAS disruptive behaviors subscale and the Present State Examination (PSE) (Wing, Cooper & Sartorius, 1974; Gibbons et al., 1984). Sensitivity of this SBAS subscale to changes in behaviors of the person with mental illness was also demonstrated (Knights, Hirsch, & Platt, 1980; Platt & Hirsch, 1981). In the present study, after modification of the questionnaire, the Cronbach's alpha coefficient was (.89). The modified version of the SBAS subscale measuring the 23 behaviors is presented in Appendix A.

Adverse Effects on the Caregivers' Lives

Adverse effects in the caregiver's life were assessed by the objective part of the Burden Assessment Scale (BAS) (Reinhard, Gubman, Horwitz, & Kinsky, 1994). The objective part of the BAS consists of 10 items which measure the impact of caregiving on social life, leisure time, finances, time off work, household relationships, relationships outside the household, impact on other family members' needs, life routine, personal plans, and caregiver's capacity to concentrate on his or her own activities. Higher scores indicate a larger number of adverse effects on the caregivers' life. Internal consistency of the objective part of the scale as measured by the coefficient alpha is excellent (.88). As a whole scale (i.e., both objective and subjective parts), the BAS differentiated between family samples with different levels of burden and was sensitive to changes over time. In the present study, the alpha coefficient was also excellent (.89). The objective part of the BAS consists of the first 10 items of the scale. The whole scale (i.e., both objective and subjective parts) is presented in Appendix B.

Quality of the Relationship Between the Caregiver and the Person with Mental Illness

Quality of the relationship between the caregiver and the ill relative was assessed by the McMaster Family Assessment Device (FAD) General Functioning subscale (Epstein, Baldwin, & Bishop, 1983). This 12-item, self-report subscale is based on the McMaster Model of Family Functioning (Epstein, Bishop, & Levine, 1978), and evaluates perceptions of the quality of the relationship with respect to mutual understanding, support, communication, acceptance, sharing, capacity to agree and to get along with one another. Higher scores on the FAD indicate relationship difficulties between the caregiver and the person with mental illness. Normative data have been computed for the FAD with families having a psychiatrically disabled member. Internal

consistency for the General Functioning subscale is very good (.84). Test-retest reliability over one week is acceptable (.71) (Miller, Epstein, Bishop, & Keitner, 1985). The FAD showed evidence of concurrent validity in presenting high correlations with the Locke Wallace Marital Satisfaction Scale (Epstein et al., 1983) and FACES II Cohesion subscales (Miller et al., 1985). It showed construct validity by differentiating between clinical and nonclinical families (Epstein et al., 1983; Miller et al., 1985). On the General Functioning subscale, the percentage of nonclinical families in the unhealthy functioning or clinical range was 22%, whereas the percentage of families with a member suffering from mental illness in the unhealthy range was 59% (Miller et al., 1985). In the present study, alpha coefficient of the General Functioning subscale of the FAD was (.87). The general functioning subscale of the FAD is presented in Appendix C.

Family Support

Family support was assessed by the Perceived Social Support from Family scale (PSS-Fa) (Procidano & Heller, 1983). The PSS-Fa is a 20-item self-report scale which assesses the perception of moral and emotional support offered by family members, as well as the sharing of ideas, feelings, and interests, closeness, honesty, empathy and companionship. Higher scores indicate a high level of perceived support from family members. The PSS-Fa shows excellent internal reliability with a Cronbach's alpha coefficient of .90. It was negatively related to psychopathology, but was unrelated to temporary attitudinal changes (induced positive and negative mood) (Procidano & Heller). The PSS-Fa was also related to a measure of family cohesion, intimacy, and to ratings of the proportion of emotional support provided by family members (Procidano & Heller). Caregivers were instructed to answer questions with regard to the support they receive from family members other than the ill relative. In this study, alpha

coefficient was (.91). The PSS-Fa is presented in Appendix D.

Satisfaction Received From Caregiving Activities

Satisfaction received from caregiving activities was assessed by the Care Work Satisfaction Scale (Orbell, Hopkins, & Gillies, 1993), a six-item self report scale which evaluates the caregiver's appraisals of self-worth gains from caregiving activities. Higher scores indicate a high level of satisfaction received from caregiving activities. The scale has demonstrated excellent internal consistency (coefficient alpha: .92), and accounted for 14% of the variance in caregiver strain in a sample of 108 primary caregivers of an older relative (Orbell et al.). Evidence of construct validity was also shown. Significant positive associations were found between Care Work Satisfaction score and Care Lifestyle Satisfaction (Orbell et al.) and a willingness to pursue caring activities (used as a criterion measure). Significant negative associations were found with Care Work Strain and Relationship Dissatisfaction Scales (Orbell et al.), the frequency of behavioral problems and assistance required by the older person in daily living activities. A factor analysis showed high loadings of the six items on the care work satisfaction factor (.65 to .87). In this study, alpha coefficient was also excellent (.95). The Care Work Satisfaction Scale is presented in Appendix E.

Sense of Mastery

Sense of mastery in caregiving was evaluated by the Mastery Scale (Pearlin & Schooler, 1978), a seven-item, self-report scale which evaluates perception of one's capacity of dealing with life events. Higher scores indicated a high sense of mastery in caregiving activities. The scale is reliable, with a Cronbach's alpha coefficient ranging from .71 to .88 in several studies (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Evidence of validity was also

demonstrated by correlations with other measures evaluating related constructs. Mastery Scale scores were negatively associated with depression symptoms as evaluated by the CES-D (Radloff, 1977), and positively associated with time spent in a caregiving role (Clair, Fitzpatrick, & LaGlory, 1995). Sense of mastery was positively associated with psychological adjustment (Bibou-Nakou, Dikaiou, & Bairactaris, 1997) as measured by the General Health Questionnaire (Goldberg, 1972), positively associated with self-esteem (Braithwaite, 1996) as measured by the Self-Esteem Scale (Rosenberg, 1965), and negatively associated with the presence of anxious and depressive symptoms (Braithwaite), as measured by the Delusions-Symptoms-States Inventory (Bedford, Foulds, & Sheffield, 1976) and the Four neurotic Symptoms Index (Henderson, Byrne, & Duncan-Jones, 1981). Caregivers were instructed to answer questions with regards to their feelings about caregiving. In the present study, the Cronbach's alpha coefficient was (.75). The Mastery scale is presented in Appendix F.

Subjective Burden

Subjective burden was assessed by the subjective part of the BAS (Reinhard et al., 1994). The subjective part of the BAS consists of nine items which evaluates the extent of subjective burden perceived by caregivers with regard to embarrassment, guilt about not doing enough and about causing the relative's illness, stigma, resentment, worries about the future and about making things worse, and feeling trapped and upset. Higher scores indicate higher feelings of SB in caregivers. Internal consistency of the subjective part of the BAS as measured by coefficient alpha is good (.80). Again, as a whole scale (i.e., both objective and subjective parts), the BAS differentiated between family samples with different levels of burden and was sensitive to changes over time. In this study, the Cronbach's alpha coefficient of the subjective part of the BAS was

(.81). As noted above, the BAS is presented in Appendix B.

Caregivers' Depressive Symptoms

The presence of depressive symptoms in caregivers was assessed by the Centre for Epidemiologic Studies Depression Scale (CES-D Scale) (Radloff, 1977). The CES-D scale is a 20-item, self-report questionnaire which evaluates depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, loss of energy, and disturbances of sleep and appetite (Radloff & Teri, 1986). Higher scores indicate higher number and severity of depressive symptoms in caregivers. The CES-D has good levels of internal consistency with highly satisfactory measures of split-half correlation (.85) and coefficient alpha (.92) (Radloff). Evidence of construct validity was also presented. The CES-D discriminated well between clinical patients and general population samples (Craig & Van Natta, 1976) and discriminated in predictable ways among subgroup of patients (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). CES-D scores also correlated with ratings of severity of depression made by clinicians familiar with patients (Weissman et al.). Concurrent validity was shown by the high correlations between CES-D and the Beck Depression Inventory and the Zung Self-Rating Depression Scale (Radloff & Teri), and with the depression subscale of the SCL-90 (Weissman et al.). Evidence of discriminant validity was shown by negative correlations between CES-D scores and Bradburn Scale of Positive Affect scores (Radloff). In this study, the Cronbach's alpha coefficient was (.90). The CES-D is presented in Appendix G.

Caregivers' Satisfaction with Life

Caregivers' satisfaction with life was assessed by the Satisfaction With Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1983), a five-item, self-report scale which evaluates global

life satisfaction. Higher scores indicate higher levels of satisfaction with life. Reliability and validity of the scale were evaluated using a sample of 176 undergraduate students. The two month test-retest correlation coefficient was .82 and coefficient alpha was .87 (Diener et al.). Scores on the SWLS were also moderately to strongly correlated with the following well-being measures: Cantril's (1965) Self-Anchoring Ladder (.62), Gurin, Veroff and Feld's (1960) widely used item (.59), Andrews and Withey's (1976) D-T scale (.68), Fordyce's (1978) single item measure of happiness (.58), Fordyce's (1978) percent of time happy question (.58), Campbell, Converse and Rodgers' (1976) semantic differential-like scale (.75), Bradburn's (1969) Affect Balance Scale (.50), and Tellegen's (1979) well-being subscale of his Differential Personality Questionnaire (.68). In the present study, alpha coefficient was (.90). The SWLS is presented in Appendix H.

Table 3 presents the Cronbach's alpha coefficients of the different measures used with the present group of caregivers.

Socio-Demographic Variables

The following socio-demographic characteristics were collected at the end of the questionnaire: caregivers' age and gender, ethnicity, family income, years of formal education of caregivers, coresidence status between the caregiver and the person with mental illness, and nature of kinship ties between the caregiver and the person with mental illness. Coresidence status, which was included in the regression equations, was transformed into a dichotomous variable coded 1 for shared residence and 0 for separate living arrangements. Because findings in the research literature suggest that other demographic variables do not predict global SB, they were not included as control variables in the present study. Information on other socio-

demographic variables was collected for descriptive purposes.

Procedure

The researcher initially contacted mental health workers responsible for conducting psycho-educational and support groups for family members and friends of individuals suffering from severe mental illness. Mental health workers were informed about the study, and the researcher asked permission to present the study to group members at the beginning of a meeting. The communication script with mental health workers is presented in Appendix I. The script used to present the study to caregivers is included in Appendix J. Pre-addressed and pre-stamped envelopes containing two copies of a consent form and the questionnaire were left to the mental health workers leading the groups, so that group members who were interested in participating could take one envelope at the end of the meeting. A consent form is included in Appendix K. Because attendance usually fluctuates throughout group sessions, some mental health workers accepted that the study be presented on a regular basis in their group, in order to reach as many members as possible. Furthermore, because some of these groups were of limited duration (8 to 12 weeks), the researcher sometimes had access to two successive groups of people associated with a same organization. Recruitment was conducted between February 1999 and September 1999.

The questionnaire included the Symptomatic Behaviors section of the Social Behavioral Assessment Schedule (Platt et al., 1980), the Family Assessment Device General Functioning subscale (Epstein et al., 1983), the Perceived Social Support from Family scale (Procidano & Heller, 1983), the Care Work Satisfaction Scale (Orbell et al., 1993), the Mastery scale (Pearlin & Schooler, 1978), the Burden Assessment Scale (Reinhard et al., 1994), the Centre for

Epidemiologic Studies Depression Scale (Radloff, 1977), and the Satisfaction With Life Scale (Diener et al., 1983). The order in which the various scales were presented in the questionnaire was rotated, in order to control for fatigue effects. Socio-demographic information were obtained at the end of the questionnaire. The questionnaire took about one hour to complete. Caregivers who completed and returned a questionnaire received \$20 by mail in compensation for their time.

Data Analysis

Each of the three research hypotheses was tested using two different methods of multiple regression analyses: (1) Standard Multiple Regression and (2) Hierarchical Multiple Regression. The Multiple Regression analyses were conducted on the whole group of caregivers. The two methods of regression analyses were used as each of them addressed a different concern. In Standard Multiple Regression, predictor variables are not ordered and they are entered as a block in the regression analysis. Each independent variable is credited with the unique variance it explains in the dependent variable. Therefore, none of the independent variable is prioritized over another one, and each independent variable is given an equal opportunity to contribute to the dependent variable. As the contribution of new predictor variables was evaluated in this study, there was a concern that accounting for the effects of symptomatic behaviors in a first step would reduce the likelihood of detecting a significant contribution of these new predictor variables on SB. Standard Multiple Regression was therefore used as a method of analysis to address this concern.

In Hierarchical Multiple Regression, predictor variables are ordered according to a theoretical model. The first variable entered is credited with both unique and shared variance contributed to the dependent variable. Each subsequent variable entered in the regression

equation is credited for the remaining unique and shared variance accounted in the dependent variable. Although Hierarchical Multiple Regression has the advantage of grounding the statistical analyses in a theoretical framework, it also increases the likelihood that the first variables entered in the analysis reach significance level and decreases the likelihood that variables entered at a later step reach significance. Hierarchical Multiple Regression was used to ground research in caregiving in severe mental illness in a theoretical framework. Variables were ordered according to a stress and coping framework which suggests that social and psychological resources either moderate or mediate the relationship between stressors and outcomes.

Results

Plan of Analyses

Initially, the data screening procedures used to ensure accuracy of input and to verify normality of distribution for the study variables are presented in the result section.

Transformations of scores that were performed are detailed in this section. Then, descriptive information is presented, including socio-demographic information and caregivers' standing on the variables included in the study. A correlation matrix presenting bivariate correlations performed on the different variables included in the Caregiver Burden model is also presented. Then, results of Standard Multiple Regression analyses for variables predicting caregivers' SB, caregivers' depressive symptoms and caregivers' satisfaction with life are presented. Finally, results of Hierarchical Multiple Regression analyses for variables predicting caregivers' SB, caregivers' depressive symptoms and caregivers' satisfaction with life are presented.

Data Screening

Data entry was compared with original answers on the questionnaires, and univariate descriptive statistics (e.g., means, standard deviations, out of range values) were verified to ensure accuracy of input. Upon receiving the questionnaires, caregivers' answers were verified to limit missing data. When demographic questions were left unanswered, caregivers were contacted by phone and information was obtained. Because some individuals are not comfortable sharing information about their income, caregivers were not contacted when they omitted answering the question about family income. Information about socio-demographic variables, with the exception of family income, was therefore complete. Information about family income was provided by 96.1% of caregivers. As family income was not entered in the regression

equation but was presented for descriptive purposes only, the average family income was computed from the information volunteered by 96.1% of the caregiver sample. Caregivers answered most questions designed to assess variables entered in the regression equations. Between 99.1% and 99.9% of questions on each measure were answered. The few questions that were left unanswered were given the average score for the question, as suggested by Tabachnick and Fidell (1989), in order to avoid deletion of cases in the regression equation resulting from missing data. The average score on a question usually reflected the "moderate" or "neither agree nor disagree" position, and therefore suggested a certain degree of ambivalence. It is believed that caregivers who did not answer a question may have been ambivalent or unsure about what to answer on that question. Most questionnaires received were complete.

Distribution of variables entered in the regression equations were verified to identify univariate outliers (i.e., scores which differed from the mean by more than three standard deviations; Tabachnick & Fidell, 1989). There were two univariate outliers found in these variables. One caregiver reported a score of 46 ($z = 3.14, p < .01$) indicating extensive relationship difficulties with the person with mental illness. This score was reduced to 43, one point higher than the second highest value, as suggested by Tabachnick and Fidell (1989). The new z score for this value was 2.65, $p < .05$. Another caregiver reported a score of 46 ($z = 3.43, p < .01$) indicating that he or she was experiencing a high number of depressive symptoms. This score was also reduced to 36, one point higher than the second highest value. The new z score for this value was 2.37, $p < .05$.

Variables were also verified to ensure normality of distribution. Variables with indices of skewness and kurtosis with $p > .01$, as suggested by Tabachnick and Fidell (1989), can be

considered normally distributed for the purpose of entry in the regression equations. Measures of skewness and kurtosis were obtained for the variables entered in the regression equations, and none of the variables had indices of skewness or kurtosis with $p < .01$. Correlational analyses showed problems of multicollinearity between adverse effects on the caregivers' lives and SB ($r = .69$). The magnitude of the correlation between adverse effects on the caregivers' lives and SB suggests the possibility that (1) these two theoretical concepts might reflect the same negative appraisal of the caregiving situation, or (2) the measures used might not discriminate adequately between these two concepts. Tabachnick and Fidell (1989) suggested not including two variables with a bivariate correlation coefficient of approximately ($r = .70$) or higher in the same analysis, because doing so weakens the analysis. They recommended either combining the two variables into a more global one, or deleting one of the two variables. The first alternative was rejected, because the selection of variables included in the study was based on their possible relationship with SB, the dependent and target variable in the study. By modifying the dependent variable, the predictor variables were becoming less relevant. The second alternative was therefore accepted and the adverse effects on the caregivers' lives variable was not entered in the regression analyses.

Descriptive Information About Caregivers

Descriptive information about caregivers is presented in Table 4. Descriptive statistics included means and standard deviations, or frequencies, for the whole group of caregivers ($N = 128$). Caregivers who participated in the study were mostly Caucasian (96%) and were approximately 50 years of age. About 72% were female, and 58% resided with the person with a mental illness. Caregivers had an average of 14 years of formal education and an annual family

income of \$40,500. Approximately 52% of caregivers were caring for an adult child, 23% were caring for a spouse, 16% were providing help to a family member other than an adult child or spouse, and 9% were caring for a friend. Caregivers who were not residing with the care recipient were providing approximately 13 hours of instrumental help or emotional support on a weekly basis to the person with a mental illness. Caregivers' standing on the measures evaluating the different variables included in the study are also presented in Table 4. Differences between the current sample of caregivers and those caregivers participating in the studies included in the literature review, and associated implications for the study findings are discussed in the discussion section.

Correlational Analyses

A correlation matrix presenting bivariate correlations performed on the different variables included in the Caregiver Burden model is presented in Table 5. Point biserial coefficients were computed for correlations between coresidence status and continuous variables (i.e., the other variables included in the model), whereas Pearson coefficients were computed for correlations between the continuous variables. Because 45 correlation coefficients were computed, Bonferroni corrections were performed to keep the overall probability of making a Type I error equal to or less than .05. Coefficients with probabilities equal to or less than .001 were considered significant. SB was significantly correlated with symptomatic behaviors of the person with a mental illness ($r = .36, p < .001$); adverse effects on caregivers' life ($r = .69, p < .001$); quality of the relationship between the caregiver and the person with mental illness ($r = .37, p < .001$); sense of mastery in caregiving ($r = -.46, p < .001$); satisfaction received from caregiving activities ($r = -.33, p < .001$); caregivers' satisfaction with life ($r = -.39, p < .001$); and caregivers'

depressive symptoms ($r = .49, p < .001$). SB was not correlated with coresidence status or family support.

Standard Multiple Regression Analyses

Results of Standard Multiple Regression analyses for variables predicting caregivers' SB, caregivers' depressive symptoms and caregivers' satisfaction with life are presented in Tables 6, 7 and 8 respectively. Information presented in Tables includes the unstandardized regression coefficients (B) and intercept, the standard error ($SE B$), the standardized regression coefficients (Beta), amount of variance explained (R^2) and probability values (p). Because three regression analyses were conducted, Bonferroni corrections were again performed to keep the overall probability of making a Type I error equal to or less than .05. Values with probabilities equal to or less than .017 were considered significant.

Research Hypothesis 1

Research hypothesis 1 predicted that low levels of SB in caregivers would be related to maintaining separate living arrangements with the care recipient, a low occurrence of symptomatic behaviors in the person with mental illness, a good relationship between the caregiver and the person with mental illness, good family support, a high sense of mastery and high levels of satisfaction received from caregiving activities. A summary of the Standard Multiple Regression analysis for variables predicting SB is presented in Table 6. Research hypothesis 1 was partially supported by the findings, with R for regression significantly different from zero, $F(6, 121) = 8.23, p < .001$. The presence of symptomatic behaviors in the person with mental illness and a sense of mastery in caregiving activities predicted SB. Residing with the person with mental illness, the quality of the relationship between the caregiver and the person with mental illness, the

presence of family support, and satisfaction received from caregiving activities were not directly related to SB. The variables, mostly symptomatic behaviors and sense of mastery, explained 25.5% of the variance in SB.

Analysis of the residuals was also performed to ensure normality of distribution. No multivariate outlier was identified using a $p < .001$ criterion for standardized residual distance (Tabachnick & Fidell, 1989). A visual verification of probability plots was performed and suggested that residuals were normally distributed.

In order to get a more accurate evaluation of the amount of variance accounted for by symptomatic behaviors and sense of mastery on SB, the standard multiple regression analysis was performed again with symptomatic behaviors and sense of mastery as the only independent variables included in the equation. In the reduced model, R for regression was significantly different from zero, $F(2, 125) = 22.45$, $p < .001$, and the two independent variables accounted for 25.2% of the adjusted variance in SB.

Research Hypothesis 2

Research hypothesis 2 predicted that low SB would be related to low levels of depressive symptoms in caregivers. Therefore, a significant proportion of the variance in depressive symptoms would be explained by SB, while controlling for the possible contribution of the other variables in the model (i.e., coresidence status between the caregiver and the person with a mental illness, symptomatic behaviors in the person with mental illness, quality of the relationship between the caregiver and the person with mental illness, family support, sense of mastery and satisfaction received from caregiving activities). A summary of the Standard Multiple Regression analysis for variables predicting caregivers' depressive symptoms is presented in Table 7.

Research hypothesis 2 was supported by the findings, with R for regression significantly different from zero, $F(7, 120) = 9.16, p < .001$. A sense of mastery in caregiving activities and SB predicted caregivers' depressive symptoms. Residing with the person with mental illness, the presence of symptomatic behaviors in the person with mental illness, the quality of the relationship between the caregiver and the person with mental illness, the presence of family support, and satisfaction received from caregiving activities were not directly related to caregivers' depressive symptoms. The variables, mostly sense of mastery and SB, explained 31.0% of the variance in caregivers' depressive symptoms.

Analysis of the residuals was again performed. No multivariate outlier was identified using a $p < .001$ criterion for standardized residual distance, and a visual verification of probability plots suggested that residuals were normally distributed.

The reduced model including the two significant independent variables, sense of mastery and SB, was tested again to obtain a more accurate account of the amount of variance explained in caregivers' depressive symptoms by the two variables. In this reduced model, R for regression was significantly different from zero, with $F(2, 125) = 25.80, p < .001$. Sense of mastery and SB explained 28.1% of the adjusted variance in caregivers' depressive symptoms.

Research Hypothesis 3

Research hypothesis 3 predicted that low SB would be related to high levels of satisfaction with life in caregivers. Therefore, a significant proportion of the variance in satisfaction with life would be explained by SB, while controlling for the possible contribution of the other variables in the model (i.e., coresidence status between the caregiver and the person with a mental illness, symptomatic behaviors in the person with mental illness, quality of the relationship between the

caregiver and the person with mental illness, family support, sense of mastery and satisfaction received from caregiving activities). A summary of the Standard Multiple Regression analysis for variables predicting caregivers' satisfaction with life is presented in Table 8. Research hypothesis 3 was supported by the findings, with R for regression significantly different from zero, $F(7, 120) = 6.83, p < .001$. SB predicted caregivers' satisfaction with life. Residing with the person with mental illness, the presence of symptomatic behaviors in the person with mental illness, the quality of the relationship between the caregiver and the person with mental illness, the presence of family support, a sense of mastery in caregiving activities and satisfaction received from caregiving activities were not directly related to caregivers' satisfaction with life. The variables, mostly SB, explained 24.3% of the variance in caregivers' satisfaction with life.

In the analysis of residuals, no multivariate outlier was identified using a $p < .001$ criterion for standardized residual distance, and a visual verification of probability plots suggested that residuals were normally distributed.

Because only SB was significantly associated with caregivers' satisfaction with life, the amount of variance explained by SB in caregivers' satisfaction with life can be obtained by squaring the correlation coefficient ($-.39$) between SB and caregivers' satisfaction with life. SB explained 15.2% of the variance in caregivers' satisfaction with life.

Hierarchical Multiple Regression Analyses

Results of Hierarchical Multiple Regression analyses for variables predicting caregivers' SB, caregivers' depressive symptoms and caregivers' satisfaction with life are presented in Tables 9, 10 and 11 respectively. Information presented in Tables includes the unstandardized regression coefficients (B) and intercept, the standard error ($SE B$), the standardized regression coefficients

(Beta), amount of variance explained (R^2) and probability values (p). Because three regression analyses were conducted, Bonferroni corrections were again performed to keep the overall probability of making a Type I error equal to or less than .05. Values with probabilities equal to or less than .017 were considered significant.

Research Hypothesis 1

To test research hypothesis 1, SB was regressed on the predictor variables. Coresidence status between the caregiver and the care recipient was first entered in the regression equation. Then, symptomatic behaviors in the person with mental illness were entered in a second step. Family resource variables including the quality of the relationship between the caregiver and the person with mental illness and family support were entered in the third step of the regression equation. Finally, positive appraisal variables including sense of mastery in caregiving and satisfaction received from caregiving activities were entered in the fourth step of the regression equation. A summary of the Hierarchical Multiple Regression analysis for variables predicting SB is presented in Table 9. R for regression was significantly different from zero, $F(6, 121) = 8.23$, $p < .001$. The presence of symptomatic behaviors in the person with mental illness and a sense of mastery in caregiving activities predicted SB. Residing with the person with mental illness, the quality of the relationship between the caregiver and the person with mental illness, the presence of family support, and satisfaction received from caregiving activities were not directly related to SB. The variables, mostly symptomatic behaviors and sense of mastery, explained 25.5% of the variance in SB. Therefore, the results obtained using a Hierarchical Multiple Regression analysis were similar to those obtained using a Standard Multiple Regression analysis.

Research Hypothesis 2

To test research hypothesis 2, depressive symptoms in caregivers were regressed on the predictor variables and SB. Coresidence status between the caregiver and the care recipient was first entered in the regression equation. Then, symptomatic behaviors in the person with mental illness were entered in a second step. Family resource variables including the quality of the relationship between the caregiver and the person with mental illness and family support were entered in the third step of the regression equation. Then, positive appraisal variables including sense of mastery in caregiving and satisfaction received from caregiving activities were entered in the fourth step of the regression equation. Finally, SB was entered in the fifth step of the regression equation, once all other predictor variables were accounted for. A summary of the Hierarchical Multiple Regression analysis for variables predicting depressive symptoms in caregivers is presented in Table 10. R for regression was significantly different from zero, $F(7, 120) = 9.16, p < .001$. Sense of mastery in caregiving activities and SB predicted the presence of depressive symptoms in caregivers. Residing with the person with mental illness, symptomatic behaviors of the person with mental illness, the quality of the relationship between the caregiver and the person with mental illness, the presence of family support, and satisfaction received from caregiving activities were not directly related to depressive symptoms in caregivers. The variables, mostly sense of mastery in caregiving activities and SB, explained 31.0% of the variance in caregivers' depressive symptoms. Again, the results obtained using a Hierarchical Multiple Regression analysis were similar to those obtained using a Standard Multiple Regression analysis.

Research Hypothesis 3

To test research hypothesis 3, caregivers' satisfaction with life was regressed on the

predictor variables and SB. Coresidence status between the caregiver and the care recipient was first entered in the regression equation. Then, symptomatic behaviors in the person with mental illness were entered in a second step. Family resource variables including the quality of the relationship between the caregiver and the person with mental illness and family support were entered in the third step of the regression equation. Then, positive appraisal variables including sense of mastery in caregiving and satisfaction received from caregiving activities were entered in the fourth step of the regression equation. Finally, SB was entered in the fifth step of the regression equation, once all other predictor variables were accounted for. A summary of the Hierarchical Multiple Regression analysis for variables predicting caregivers' satisfaction with life is presented in Table 11. R for regression was significantly different from zero, $F(7, 120) = 6.83$, $p < .001$. SB was the only variable that predicted caregivers' satisfaction with life. Residing with the person with mental illness, symptomatic behaviors of the person with mental illness, the quality of the relationship between the caregiver and the person with mental illness, the presence of family support, satisfaction received from caregiving activities and sense of mastery in caregiving were not directly related to caregivers' satisfaction with life. The variables, mostly SB, explained 24.3% of the variance in caregivers' satisfaction with life. Again, the results obtained using a Hierarchical Multiple Regression analysis were similar to those obtained using a Standard Multiple Regression analysis.

Additional Analyses

Because research hypothesis 1 was only partially supported, and because variables such as coresidence status between the caregiver and the person with mental illness, quality of the relationship between the caregiver and the person with mental illness, family support and

satisfaction received from caregiving activities were not directly associated with SB, additional analyses were conducted to examine whether these variables were associated indirectly with SB by acting as moderators or contributing to a mediating relationship with SB.

Moderation Analyses

Because coresidence status between the caregiver and the person with mental illness was not correlated with SB or with any other predictor variables, the hypothesis that coresidence status might have acted as a moderator variable and affected the relationships between SB and other predictor variables was investigated. As indicated by Baron and Kenny (1986), a moderating effect between a moderator variable (dichotomous) and an independent variable (continuous) is best evaluated by comparing the unstandardized regression coefficients of the dependent variable on the independent variables for each level of the moderator (i.e., caregivers residing with the person with mental illness and those maintaining separate living arrangements), using the test of the difference between regression coefficients. The total sample of caregivers was therefore divided in two groups: those residing with the person with mental illness ($n = 74$) and those maintaining separate living arrangements ($n = 54$). SB was regressed on the following independent variables (i.e., symptomatic behaviors of the person with mental illness, quality of the relationship between the caregiver and the person with mental illness, family support, sense of mastery in caregiving and satisfaction received from caregiving activities).

Descriptive statistics (i.e., means and standard deviations) of the variables included in the regression analyses for both groups of caregivers are presented in Table 12. A visual verification of caregivers' scores on each variable suggests that the two groups of caregivers did not differ on any of the variables included in the moderation analyses. Results of the two standard multiple

regression analyses are presented in Table 13 and include the unstandardized regression coefficients (B) and intercept, the standard error ($SE B$), and the standardized regression coefficients (Beta). F ratio, Sum of Squares of residuals (SSE), amount of variance explained (R^2) and probability values (p) are also indicated for each regression analyses. Because two regression analyses were conducted to test the moderator effect of coresidence status, Bonferroni corrections were again performed to keep the overall probability of making a Type I error equal to or less than .05. Values with probabilities equal to or less than .025 were considered significant in the moderation analyses. For caregivers residing with the person with mental illness, the regression equation was significantly different from zero, with $F(5, 68) = 3.60, p < .01$. The five independent variables explained approximately 15% of the variance in SB. Symptomatic behaviors in the person with mental illness was the only variable significantly associated with SB. For caregivers maintaining separate living arrangements, the regression equation was also significantly different from zero, with $F(5, 48) = 6.89, p < .001$. The five independent variables explained approximately 36% of the variance in SB. Sense of mastery in caregiving activities was the only variable significantly associated with SB.

The test of the difference for regression coefficients was conducted using the formula given in Berenson, Levine and Goldstein (1983):

$$t = \frac{bc - bs}{\sqrt{\left[\frac{SSEc + SSEs}{nc + ns - 4} \right] \left[\frac{1}{(nc - 1) S^2_{xc}} + \frac{1}{(ns - 1) S^2_{xs}} \right]}}$$

where caregivers residing with the care recipient and those maintaining separate living

arrangement were represented respectively by the letters "c" and "s". Unstandardized regression coefficients (b) of the independent variable, Sum of Squares of residuals (SSE), number of participants in each group (n), and variance (S^2x) of the independent variable were also included in the equation. Because the difference between the regression coefficients of five independent variables were tested, Bonferroni corrections were performed to keep the overall probability of making a Type I error equal to or less than .05. Alpha level for each test of the difference between regression coefficients was therefore reduced to .01. Results indicated that one independent variable, sense of mastery in caregiving activities, had regression coefficients that were significantly different from one another in the two groups ($t(120) = -4.82, p < .005$), in the presence of a main effect of the independent variable on the dependent variable in one of the groups. These results suggest an interaction effect between coresidence status and sense of mastery, with sense of mastery being more strongly associated with SB for caregivers maintaining separate living arrangements than for those residing with the person with mental illness.

Results also indicated that a second independent variable, quality of the relationship between the caregiver and the person with mental illness, had regression coefficients that were statistically different from one another in the two groups ($t(120) = -2.84, p < .005$). However, it is believed that statistical significance in the latter case was reached because of a crossover interaction (i.e., a change from negative to positive regression coefficient). Although strong statistically, a crossover interaction, when not accompanied by a residual main effect of the independent variable, may suggest a moderation effect that is not relevant from a conceptual perspective (Baron & Kenny, 1986). The difference between regression coefficients of the quality of the relationship variable was therefore not interpreted.

Mediation Analyses

Mediating effect of sense of mastery for the whole group of caregivers. Given the association between sense of mastery in caregiving activities and SB, additional analyses were also conducted to examine whether a good relationship between the caregiver and the person with mental illness, the presence of family support and satisfaction received from caregiving activities were indirectly reducing SB by increasing sense of mastery. To test these hypotheses, mediation analyses described by Baron and Kenny (1986) were performed to determine if (a) any of these three independent variables (i.e., quality of the relationship between the caregiver and the person with mental illness, family support and satisfaction received from caregiving activities) were related to both sense of mastery and SB and (b) the introduction of sense of mastery in the regression equations reduced the significance of the independent variables on SB.

According to Baron and Kenny (1986), to test for mediation, three regression equations must be performed: (a) regressing the mediator on the independent variable; (b) regressing the dependent variable on the independent variable; and (c) regressing the dependent variable on both the independent variable and the mediator. To establish mediation, the following conditions must be met: (a) the independent variable must affect the mediator in the first equation; (b) the independent variable must affect the dependent variable in the second equation; and (c) the mediator must affect the dependent variable in the third equation (Baron and Kenny, 1986). If these conditions are met, then the effect of the independent variable on the dependent variable must be less in the third equation than in the second. The difference between the effect of the independent variable on the dependent variable in the second and third equations is estimated using, as suggested by Baron and Kenny (1986), the test of the difference between regression

coefficients provided by Sobel (1982):

$$t = \frac{b_i - b_{ii}}{\sqrt{c^2 sa^2 + a^2 sc^2 + sa^2 sc^2}}$$

where b is the regression coefficient of the dependent variable on the independent variable in the second (i) and third (ii) regression equation. The path from the independent variable to the mediator is denoted as (a) and its standard error is (sa). The path from the mediator to the dependent variable is denoted as (c), and its standard error is (sc). More information with regard to the statistical analyses required to evaluate a mediation model are provided by Baron and Kenny (1986) and Sobel (1982).

The mediation analyses described above were conducted to examine whether quality of the relationship between the caregiver and the person with mental illness, family support and satisfaction received from caregiving activities were indirectly reducing SB by increasing sense of mastery. Because the difference between the regression coefficients of three independent variables were tested, Bonferroni corrections were performed to keep the overall probability of making a Type 1 error less than .05. Alpha level for each test was therefore reduced to .01. Results indicated that the quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities were significantly associated with sense of mastery, which in turn was associated with SB. Therefore, the quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities contributed indirectly to SB through their impact on sense of mastery.

First, sense of mastery was regressed on quality of the relationship between the caregiver

and the person with mental illness. Quality of the relationship between the caregiver and the person with mental illness was associated with sense of mastery, with $F(1; 126) = 40.23, p < .001$. The quality of the relationship between the caregiver and the person with mental illness variable explained 23.6% of the variance in sense of mastery. As the first condition for mediation was met, SB was then regressed on the quality of the relationship between the caregiver and the person with mental illness variable alone, and again on both the quality of the relationship variable and sense of mastery. Results are presented in Table 14. The regression of SB on the quality of the relationship between the caregiver and the person with mental illness variable was significant with $F(1; 126) = 19.60, p < .001$. The regression of SB on both the quality of the relationship variable and sense of mastery was also significant, with $F(2; 125) = 19.56, p < .001$. Finally, the effect of the quality of the relationship variable on SB was significantly less in the latter regression when mastery was included as a predictor using $t(120) = 3.44, p < .01$. The quality of the relationship between the caregiver and the person with mental illness was positively associated with sense of mastery in caregiving, which in turn was negatively associated with SB. Therefore, sense of mastery was a mediator variable between quality of the relationship between the caregiver and the person with mental illness and SB.

Second, sense of mastery was regressed on satisfaction received from caregiving activities. Satisfaction received from caregiving activities was associated with sense of mastery, with $F(1; 126) = 20.92, p < .001$. Satisfaction received from caregiving activities explained 13.6% of the variance in sense of mastery. As the first condition for mediation was met, SB was then regressed on satisfaction received from caregiving activities alone, and again on both satisfaction received from caregiving activities and sense of mastery. Results are presented in Table 15. The

regression of SB on satisfaction received from caregiving activities was significant with $F(1; 126) = 15.47, p < .001$. The regression of SB on both satisfaction received from caregiving activities and sense of mastery was also significant, with $F(2; 125) = 19.86, p < .001$. Finally, the effect of satisfaction received from caregiving activities on SB was significantly less in the latter regression when mastery was included as a predictor using $t(120) = 3.28, p < .01$. Satisfaction received from caregiving activities was positively associated with sense of mastery in caregiving, which in turn was negatively associated with SB. Therefore, sense of mastery was a mediator variable between satisfaction received from caregiving activities and SB.

Third, sense of mastery was regressed on family support. Family support was associated with sense of mastery, with $F(1; 126) = 11.11, p = .001$. Satisfaction received from caregiving activities explained 7.4% of the variance in sense of mastery. As the first condition for mediation was met, SB was then regressed on family support alone. The regression of SB on family support was not significant with $F(1; 126) = 1.38, p = .243$. As the second condition for mediation was not met, the mediation analyses including family support were discontinued. Therefore, sense of mastery was not a mediator variable between family support and SB.

A path diagram of the significant relationships identified by study findings is presented in Figure 1. Unstandardized regression coefficients obtained from Standard Multiple Regression analyses, as well as relationships identified through moderation and mediation analyses are presented in the figure. Variables are presented according to a stress and coping theoretical framework, where the relationship between stressors and outcomes is moderated and mediated by resource and appraisal variables.

Of note, as SB was predicted by both symptomatic behaviors of the person with mental

illness and sense of mastery, symptomatic behaviors could have also been used as a mediator. Sense of mastery was preferred over symptomatic behaviors as stress theory suggests that the relationship between stressors (i.e., symptomatic behaviors in the present study) and outcome variables (i.e., SB in the present study) is moderated and mediated by social and psychological resources (i.e., sense of mastery was included in the present study). Furthermore, although it would have made sense to suggest that relationship difficulties between the caregiver and the care recipient had an impact on symptomatic behaviors, it would have been more difficult to explain how family support and satisfaction received in caregiving activities could have directly contributed to symptomatic behaviors. Therefore, from both a logical and a theoretical perspective, sense of mastery was selected over symptomatic behaviors as a mediator.

Mediating effect of sense of mastery for the two residential groups of caregivers. Because prior analyses showed that coresidence status between the caregiver and the care recipient moderated the effect of sense of mastery on SB, the mediating effects of sense of mastery between SB and the three variables (i.e., relationship difficulties, family support and satisfaction received from caregiving activities) was tested on each residential group separately. Results are presented in Table 16 to 21. For caregivers sharing residence with the care recipient, conditions for mediation were not met for any of the three predictor variables. Results of these mediation analyses are presented in Tables 16 to 18.

For caregivers maintaining separate living arrangements, conditions for mediation were met for two variables: relationship difficulties and satisfaction in caregiving activities. For this group of caregivers, conditions for mediation were not met for family support. Results of these mediation analyses are presented in Tables 19 to 21. The difference between unstandardized

regression coefficients was significant for relationship difficulties (Table 19) and for satisfaction in caregiving (Table 21). This means that for caregivers maintaining separate living arrangements, relationship difficulties and satisfaction in caregiving predicted sense of mastery, which in turn predicted SB.

Results obtained from mediation analyses conducted on the whole group of caregivers are therefore similar to those obtained from mediation analyses conducted on the group of caregivers who maintained separate living arrangement with the care recipients. The same findings were not obtained in the group of caregivers sharing residence with the care recipient. This suggests that for caregivers sharing residence with the care recipient, factors other than relationship difficulties and satisfaction received from caregiving activities influence sense of mastery in caregiving.

Discussion

This study was designed to identify relationships between coresidence status between the caregiver and the person with mental illness, stressor variables (symptomatic behaviors of the person with mental illness and adverse effects on the caregivers' lives), family resource variables (quality of the relationship between the caregiver and the person with mental illness and family support), positive appraisal variables (sense of mastery in caregiving and satisfaction received from caregiving activities), adaptation outcome variables (caregivers' satisfaction with life and caregivers' depressive symptoms) and SB in family members or friends caring for a person with severe mental illness. Results indicated that the presence of symptomatic behaviors in the person with mental illness and caregivers' sense of mastery in caregiving activities predicted SB in caregivers. SB, in turn, predicted caregivers' depressive symptoms and satisfaction with life. Additional analyses suggested that coresidence status between the caregiver and the person with mental illness moderated the relationship between sense of mastery in caregiving and SB. For caregivers maintaining separate living arrangements with the person with mental illness, sense of mastery in caregiving had a stronger negative association with SB than for caregivers residing with the care recipient. Additional analyses also suggested that sense of mastery in caregiving mediated the association between SB and the following variables: quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities. In other words, the quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities were directly associated with sense of mastery, which in turn was directly associated with SB. The mediating effect of sense of mastery between SB and the two predictor variables (i.e., quality of the relationship

between the caregiver and the care recipient and satisfaction received from caregiving activities) was observed for the whole group of caregivers and for those maintaining separate living arrangement with the care recipient. This mediating effect was not observed for caregivers sharing residence with the care recipient. Overall, the findings were consistent with a stress and coping framework, where social and psychological resources moderate and mediate the relationship between stressors and outcomes.

Descriptive Statistics About Caregivers

With respect to age, gender and kinship with the person with mental illness, caregivers who participated in this study were similar to those who participated in studies included in the literature review. However, caregivers in the present study were more likely to be Caucasian, had on average an additional 18 months of formal education and had a higher family income than the average caregiver included in other studies. Of note, several studies included in the literature review were conducted in the United States and family income was reported in US currency. The differences observed between caregivers of the present study (recruited exclusively from support groups) and those of other studies (recruited from both support groups and health care facilities) were consistent with findings of Lefley (1996) showing that support group members tend to be predominantly Caucasian, and have higher levels of education and income than non-members. Also, compared to caregivers of other studies included in the literature review, a higher percentage of caregivers of the present study were residing with the person with mental illness. For caregivers who maintained separate living arrangements with the person with severe mental illness, the number of hours of care provided weekly to the care recipient (12.9) was slightly higher than the average of 9.7 hours reported in an Ontario Health Survey which included 32 000

households (Cochrane, Goering, & Rogers, 1997). However, the Ontario Health Survey included, in addition to caregiving in severe mental illness, a variety of disabilities such as chronic illness, old age and mental retardation. The comparisons mentioned above between caregivers of the present study and caregivers of studies included in the literature review were not formal (i.e., *t*-tests were not conducted).

Relationship Between Variables and SB

Relationship Between Coresidence Status and SB

Study findings did not support a direct relationship between coresidence status and SB. Therefore, in the present study, residing with the person with mental illness did not directly result in higher SB for the caregiver. However, coresidence status moderated the relationship between sense of mastery and SB. In the context of separate residence, sense of mastery had a stronger negative association with SB than was found in the context of shared residence. In other words, for a caregiver maintaining separate living arrangements, sense of mastery in caregiving was more important in reducing SB than it was for caregivers residing with the person with mental illness.

One may wonder why sense of mastery in caregiving would be more strongly associated with SB under the condition of separate residence. A possible explanation involves the nature of contacts between caregivers and care recipients. Caregivers sharing residence with the person with mental illness are likely to spend a lot of time with care recipients, with only a part of this time being devoted to caregiving activities. On the other hand, because caregivers maintaining separate living arrangements with the care recipient spend a smaller number of hours in contact with the care recipient, it is possible that they devote a larger proportion of this time to caregiving activities. If this hypothesis is correct, it would therefore make intuitive sense that sense of

mastery would be more important in caregivers' SB under the condition of separate living arrangements.

The lack of direct relationship between coresidence status and SB observed in the present study is not consistent with previous findings of the caregiving literature in severe mental illness, which suggest that residing with the person with mental illness was associated with higher OB and SB. In addition, correlational analyses of the present study did not support a relationship between coresidence status and either adverse effects on the caregiver's life or SB. It is possible that the large number of hours of involvement in caregiving activities reported by caregivers maintaining separate living arrangements in the current sample (approximately 13 hours) might have been responsible for the absence of a direct relationship between coresidence status and burden. One can imagine that caring for another person outside of one's home setting for an average of 13 hours a week is likely to be a major disruption on the caregiver's life and is likely to have implications on the caregiver's well-being, including feelings of SB. Therefore, it appears that the resulting impact on the caregiver living separately and being involved 13 hours a week in caring for a person with mental illness outside the caregiver's home, might not be different from the impact of caring for a person with mental illness under the condition of shared residence.

The difference in level of involvement in caregiving activities between the current sample of caregivers who were maintaining separate living arrangements with the person with mental illness and caregivers in the studies which found a positive relationship between shared residence and SB could not be evaluated, as studies used a variety of ways to estimate involvement. For example, Seltzer et al. (1997) evaluated the number of tasks with which the caregiver was helping the person with mental illness, but gave no indication about the amount of time the caregiver

spent helping the care recipient with those tasks. Solomon and Draine (1995) evaluated the number of phone calls and face to face contact occurring in a one month period, but again did not provide indication about the amount of time these contacts represented. It was therefore not possible to evaluate if caregivers who were maintaining separate living arrangements in the present study were more involved in caregiving activities than those of other studies who found a positive relationship between coresidence and SB.

Relationship Between Stressor Variables and SB

As repeatedly shown in the research literature, symptomatic behaviors of the person with mental illness were directly associated with SB. This was expected because the symptomatic behaviors variable is found in the research literature to be the variable most strongly and most consistently associated with SB. In this regard, the current sample of caregivers responded in a way similar to caregivers participating in other research projects.

In the present study, adverse effects on the caregiver's life was the variable most strongly associated with SB ($r = .69$). This suggests that approximately 48% (correlation coefficient squared) of the variance in adverse effects and SB was shared. Two other studies in the research literature in caregiving in severe mental illness reported findings about the relationship between adverse effects and SB. Potasznik and Nelson (1984) found a similar correlation ($r = .71$) between the two constructs. Thompson and Doll (1982) categorized adverse effects on the caregiver's life and SB according to three levels: none, moderate and severe. They reported that the incidence of adverse effects was almost identical to the incidence of SB in each level. The strength of the association reported in these two studies and in the present study raises doubts about the nature of the constructs measured. If these findings are replicated on other samples of

caregivers using a variety of measurement instruments to assess burden, the capacity of empirical findings to support adverse effects and SB as distinct constructs should be questioned. Although the distinction between adverse effects on the caregiver's life and SB is clear from a theoretical perspective, it is difficult to differentiate these constructs empirically. These findings also suggest that any intervention targeting the reduction of adverse effects in the caregiver's life such as the provision of instrumental help and respite services are likely to result in a decrease in SB.

Relationship Between Family Resource Variables and SB

The assumption that family resource variables (i.e., quality of the relationship between the caregiver and the person with mental illness and family support) would directly contribute to explain variance in SB was not supported in the present study. However, findings suggest that relationship difficulties between the caregiver and the person with mental illness contributed to reduce caregivers' sense of mastery, which in turn contributed to increase SB. Therefore, the quality of the relationship between the caregiver and the person with mental illness contributed to SB indirectly through its effects on sense of mastery. Correlational analyses in the present study indicated a positive association ($r = .44$) between symptomatic behaviors of the person with mental illness and relationship difficulties between the caregiver and the person with mental illness. These findings were consistent with conclusions reported by Pickett, Cook, Cohler, and Solomon (1997) indicating that severe mental illness resulted in a poorer quality of caregiver/ care recipient interactions and a greater degree of conflict. It is possible that symptomatic behaviors of the person with mental illness contribute to relationship difficulties between the caregiver and the care recipient, which in turn affect sense of mastery in the caregiver, and which in turn affect SB.

Non replicated findings about caregiving in mental illness showed direct associations

between SB and some aspects of the relationship between the caregiver and the person with mental illness (i.e., intimacy and conflict). In this study, the quality of the relationship between the caregiver and the person with mental illness was evaluated globally and included mutual understanding, reciprocal support, opportunity to share feelings and to confide in one another, mutual acceptance, ability to make consensual decisions and ability to get along with one another.

The measure strongly emphasized the reciprocity of support and other positive aspects of a relationship. Some caregivers commented on this issue and indicated that although they felt supportive and accepting of the care recipient, they did not always feel that the care recipient could provide them with equal amounts of support and acceptance. Because the nature of caregiving activities in severe mental illness imply that an individual takes on a helping role toward a vulnerable, and at times unstable individual, it is possible that the General subscale of the FAD, with its emphasis on reciprocity, may not be an appropriate measure for the quality of the relationship between the caregiver and the care recipient. Measures designed to evaluate aspects of the relationship such as conflict and intimacy, and perhaps other aspects such as communication and problem solving, may be more appropriate in caregiving in severe mental illness than those designed to evaluate constructs like reciprocity, roles or affective responsiveness.

The results of the present study contrast with findings of the literature about caregiving for older persons with cognitive impairment. In the latter literature, quality of the relationship between the caregiver and the older person with cognitive impairment was directly associated with both positive appraisal variables and SB. In addition to possible differences in the measurement of the quality of the relationship variable, the specific characteristics of severe

mental illness and those of degenerative illness may have contributed to the differences observed in the findings. Because the onset of a degenerative illness occurs usually at a later time in the life cycle, the caregiver of a person with a degenerative illness may have experienced a time where his or her relationship with the care recipient was more stable and reciprocal (i.e., not affected by the illness). It may be easier for the caregiver to identify aspects of the relationship that have changed as a result of the illness, to be more able to differentiate the conflicts and hardships that are a result of the illness and therefore to be more tolerant of these conflicts and hardships. On the other hand, the onset of severe mental illness in late adolescence and early adulthood may make it more difficult for the caregiver to think of a time where his or her relationship with the adult care recipient was stable and not affected by the illness, and to see how the illness has affected that relationship. In other words, the ability of caregivers to attribute some conflicts and difficulties in the relationship to symptoms or consequences of the illness, and not to the person with mental illness per se, may mediate the association between the quality of the relationship and SB.

In addition to the early onset of severe mental illness, the cyclical nature of symptoms in severe mental illness may lead some caregivers to believe that the symptomatic behaviors of persons with mental illness are under the control of clients and result in caregivers attributing disruptive behaviors and conflicts to the individual with mental illness, as opposed to attributing them to the illness itself. Greenberg, Kim et al. (1997) showed that caregivers who viewed the care recipients' behaviors as outside their control exhibited lower levels of SB than those who viewed the symptomatic behaviors as within the control of care recipients. Overall, it is possible that caregivers' attributions with regard to the symptomatic behaviors influence their perception of their relationship with the care recipients, and mediated the association between the quality of the

relationship and SB.

Findings of the present study indicated that family support, the second family resource variable, was not related to SB. The inclusion of the family support variable was based on the assumption that the large amount of time taken by caregiving would tend to isolate caregivers from other social contacts and activities. As a result, the family would take increasing importance for caregivers. It is possible that because caregivers are already highly devoted to a family member, their feelings of burden are reduced by contact and support from the "outside world" as opposed to the support coming from family members. In support of this hypothesis is Spaniol's (1987) exploratory study findings of family members caring for a relative with mental illness, who identified the following coping strategies as part of their successful coping styles: involvement in outside activities; engaging in meaningful work away from home; making efforts in order to maintain a normal family life; and belonging to a support group.

The way in which family support was measured may also be responsible for the discrepancy observed between the initial positive correlation found between family support and SB (Potaszniak & Nelson, 1984) and the present study findings. Potaszniak and Nelson measured family support in terms of the amount of time the caregiver' spouse spent with the adult child with mental illness, whereas in this study, family support was measured in terms of the perceived quality of support received by family members other than the person with mental illness. Therefore, it was not possible to conclude whether the differences in findings were the result of the nature of family support provided (i.e., instrumental vs. emotional), or the result of the kinship between the caregiver and the support provider (i.e., spouse vs. any family member other than the person with mental illness).

Another possible explanation for the lack of relationship between SB and family support lies in the selection procedure. Participants in the study were people who had already sought support from an external source with regard to their caregiving activities. It is possible that these caregivers did not perceive the support offered by other family members as effective in fulfilling their needs and in alleviating their feelings of SB.

Relationship Between Positive Appraisal Variables and SB

The assumption that positive appraisal variables (i.e., sense of mastery in caregiving and satisfaction received from caregiving activities) would directly contribute to explain variance in SB was partially supported by the present study findings. Sense of mastery directly contributed to explain variance in SB, whereas satisfaction received from caregiving activities did not. However, additional analyses showed that satisfaction received from caregiving activities was directly related to sense of mastery, which in turn contributed to SB.

The relationship between feelings of mastery and SB was previously demonstrated in studies of caregiving for persons with severe mental illness (Noh & Avison, 1988; Solomon & Draine, 1995). These findings were replicated in the present study, indicating again that the caregivers' feelings of competence in their ability to assess the needs of the person with mental illness and to provide for those needs were negatively associated with SB. These findings are also consistent with the literature in caregiving for an older person with cognitive impairment, which showed that sense of mastery was negatively related to measures of SB (Aneshensel et al., 1995). These findings provide support for the assumption that the ability to positively appraise aspects of caregiving reduces SB experienced by the caregiver.

Satisfaction received from caregiving activities was not directly related to SB. However,

it was directly related to sense of mastery, which in turn directly contributed to SB in caregivers. Sense of mastery therefore mediated the relationship between satisfaction received from caregiving activities and SB. The absence of a direct relationship between SB and satisfaction received from caregiving activities when caring for people with a severe mental illness contrasts with findings of the research literature in caregiving for older people with cognitive impairment, where these two variables were directly related. Possible explanations for these findings include, again, the nature of severe mental illness and the way SB was measured. Severe mental illness involves cycles of exacerbation and remission of symptoms. Although a dementia illness also involves variations in cognitive and emotional status, there is a global continuous decline in the cognitive capacities of the individual. Well-being of the person with severe mental illness tends to be less predictable, which may make caregiving in severe mental illness a more stressful, and therefore, a less satisfying experience. In a study of caregivers in severe mental illness, Winefield and Harvey (1994) found that caregiving gratification was contingent on whether the person with mental illness was symptomatic or was relatively well (i.e., stable). It is possible that the condition of the person with mental illness (i.e., symptomatic or relatively well) may have influenced caregivers' level of satisfaction received from caregiving activities and sense of mastery, which in turn is directly associated with SB. Correlations between symptomatic behaviors and sense of mastery ($r = -.31, p < .001$), and between symptomatic behaviors and satisfaction received from caregiving activities ($r = -.31, p < .001$), are consistent with this explanation.

In addition to the nature of severe mental illness, the way SB was measured may also have contributed to the differences in findings observed between the two population of caregivers. In

the present study, SB was measured in terms of worries, guilt, stigma, resentment, embarrassment and feelings of being trapped. Whereas feelings of resentment and of being trapped may be reduced by satisfaction in caregiving, other feelings such as worrying about the future of the person with mental illness, feeling guilty about having caused the illness, or about reacting in ways which could have a negative impact on the illness, may be less likely to be directly reduced by satisfaction received from caregiving activities. Because the worries and guilt feelings described above are more characteristic of caregiving in mental illness than they are of caregiving for an older person with cognitive impairment (for example, caregivers of older persons with cognitive impairment are often younger or more healthy than the person with the illness, therefore less likely to worry about the future of the person with the illness when they will be gone; caregivers of older persons with cognitive impairment are less likely to have been blamed by mental health professionals for being the cause of the care recipient's illness), a direct relationship between satisfaction in caregiving activities and SB for caregivers for persons with severe mental illness may be less likely than for caregivers for older adults with cognitive impairment.

A few comments about differences between caregiving for people with severe mental illness and caregiving for older people with cognitive impairment have been offered in the discussion section. These comments should not in any way suggest that the burden of caring for an older person with cognitive impairment is less than the one associated with caring for a person with severe mental illness. These comments only suggest that feelings of burden in these two populations of caregivers may be affected by different factors. Given the findings of the present study, it is possible that characteristics specific to caregiving in mental illness make it less likely that feelings of satisfaction received from caregiving activities will directly contribute to reduce

SB when SB is measured in terms of the factors mentioned above (i.e., worries, guilt, stigma, resentment, embarrassment and feelings of being trapped).

Relationship Between Adaptation Outcome Variables and SB

Research hypothesis 2, which stated that a significant proportion of the variance in caregivers' depressive symptoms would be explained by SB was supported by findings of the present study. Overall, sense of mastery in caregiving activities and SB explained 28.1% of the variance in depressive symptoms in caregivers. These findings were consistent with those of Greenberg et al. (1997) and Song et al. (1997), who also found a relationship between SB and depressive symptoms in caregivers for people with severe mental illness. The findings of the present study were also consistent with those reported in the caregiving literature for older persons with cognitive impairment (Aneshensel et al., 1995; Lawton et al., 1989; Lawton et al., 1991), and suggest that the experience of SB is associated with psychosocial adjustment and feelings of negative well-being in the caregiver. In addition, because a sense of mastery in caregiving activities was related to both SB and depressive symptoms in caregivers, the use of psycho-educational groups to improve caregivers' ability to cope with disruptive behaviors of the person with mental illness and negative effects of the illness on family life might improve not only sense of mastery in caregivers but also lessen their feelings of SB and depressive symptoms, therefore improving their overall well-being.

Because some symptoms characterize both SB and depression (i.e., feeling guilty, worried, trapped), the strong relationship between the two variables was expected. By definition, SB is determined by negative feelings associated with the caregiving situation whereas depression may be influenced by all aspects of the caregiver's life. Therefore, a change in the caregiving situation

may have a more direct impact on SB than on caregivers' depressive symptoms. Furthermore, the presence of depressive symptoms in some caregivers may reflect a chronic condition whether they are the result of an affective disorder in the caregiver, or simply a negative response to years of distress.

Research hypothesis 3, which stated that a significant proportion of the variance in caregivers' satisfaction with life would be explained by SB was supported by findings of the present study. SB explained 15.2% of the variance in caregivers' satisfaction with life. Traditionally, adaptation outcomes were evaluated in terms of psychological dysfunctions and maladaptation, and little attention was given to positive outcomes of adaptation. In recent years, studies of SB in caregiving for older persons with cognitive impairment included positive adaptation outcomes and found that SB was negatively associated with the experience of positive affect. The findings of the present study suggest that empirical results reported in the research literature of caregivers for older persons with cognitive impairment (Lawton et al., 1991; Lawton et al., 1992) were also characteristic of caregivers for persons with severe mental illness. The present study findings offer a special contribution to the research literature in caregiving for persons with mental illness, as none of the previous studies reviewed attempted to test the hypothesis that SB was related to a positive measure of psychological well-being.

Because the design of this study was cross sectional, inferences could not be made about the direction of relationships between SB and the different variables. This limitation of the research design takes on special importance with the adaptation outcome variables, since the research literature on stress and coping (Lazarus & Folkman, 1984) suggest that appraisal of a situation influences adaptation outcomes. However, it makes intuitive sense to believe that when

coping with a chronic stressor, adaptation to one's situation, in turn influences appraisal of one's activities. Smith (1996) used structural modelling analyses and studied the experience of mothers caring for an adult child with mental retardation, including their feelings of SB and positive psychological well-being as measured by the Ego Integrity subscale of the Ego Adjustment scale developed by Boylin, Gordon, and Nehrke (1976). This scale requires the caregiver to indicate to what extent he/ she agrees with statements such as "Life has been good" and "I am discontented with life". Smith found that although SB did not have an impact on positive well-being, positive well-being did influence perception of SB. Future studies in caregiving for a person with mental illness should use longitudinal designs and statistical analyses (i.e., path analyses, LISREL) designed to evaluate the direction of the relationship between appraisal and adaptation outcomes on one another.

Limitations of the Present Study

The most important limitations identified in the present study were related to (1) the generalizability of the study findings, (2) the gender specificity of findings, (3) the small sample size, (4) the increased probability of making a Type I error in the additional analyses conducted, and (5) the research design.

Findings of the present study represent the experience of caregivers who were members of support and psycho-educational groups; they do not necessarily represent the experience of all caregivers of family members with mental illness. Caution should be exercised when generalizing these study findings to other caregivers. Some differences between support group members and non-members have been highlighted in the literature. Replicated findings showed that support group members tend to be predominantly Caucasian, and that they have higher levels of

education and income than do non-members (Lefley, 1996). Support group members and non-members did not differ on measures of social support (Brady, Goldman, & Wandersman, 1994; Norton, Wandersman, & Goldman, 1993). However, Mannion, Meisel, Solomon and Draine (1996) found that group members reported smaller social networks. Mixed findings with regard to SB were reported for both members and non-members of support groups. Brady et al. found that support group members reported more feelings of guilt and stigma than non-members, whereas Mannion et al. found that group members reported lower levels of subjective burden than non-members. However, the Mannion et al. sample of participants included more Blacks than the Brady et al. sample, and Blacks usually report less caregiver burden. Furthermore, approximately 40% of questionnaires left in support groups were completed by caregivers and returned (Mannion et al.). The body of data on support group members indicate that members who return surveys are mostly Caucasian, female, middle class, and educated parents (Mannion et al.). It is possible that caregivers who volunteered to participate in the study differed from caregivers who decided not to participate with regard to their experience in caregiving. These differences between caregivers should be kept in mind when generalizing the present study findings.

Participants were recruited from groups that offered support and psycho-education on severe mental illness and strategies for coping with disruptive behaviors. Interestingly, symptomatic behaviors and sense of mastery were the two variables that predicted SB. It is likely that people will chose to be part of a group if the group addresses concerns that are relevant to them. Again, it is possible that these variables be less important in predicting SB in caregivers who are not group members.

A second important limitation of the study is the extent that the findings are reflective of

the experience of female caregivers. The study sample included a disproportionate percentage of female caregivers (72%). This percentage is similar to the one found in the research literature and is most likely representative of the gender breakdown of caregivers in the population. Although research findings in the caregiving literature have demonstrated that gender did not predict the amount of SB reported by caregivers, it is possible that male and female caregivers experience caregiving in a different way, and that SB in these two groups of caregivers is affected by different variables. The reader should keep in mind that mothering has been and continues to be a central and crucial role for most women (Cook, 1988). In addition, caregivers studied in the last two decades were often parents of an adult child with a severe mental illness. Because of their limited access to education in the past decades, women in this cohort of the population were less likely to have developed a career and established themselves on a professional level. For several women, the most important roles they have fulfilled were those of a spouse and a parent. Furthermore, the literature on expressed emotions which dominated this field of research 10 to 20 years ago suggested that some causes and contributing factors to severe mental illness included inadequate parenting skills and dysfunctional family communication patterns. These societal and clinical attributions may have led to a greater emotional investment of females in the caregiver role (Cook, 1988), and may have therefore placed females at a higher risk to experience feelings of burden. Carpentier et al. (1992) studied how single parents (males and females) cared for their adult child with severe mental illness. They reported that male caregivers provided financially for the adult child but usually delegated the caregiving duties to another person, whereas female caregivers took responsibility for both types of duties (financial and direct care). These multiple responsibilities that female caregivers tend to accept contribute to making caregiving in severe

mental illness a more demanding experience and place female caregivers at a higher risk for experiencing burden.

A third important limitation of the present study refers to the small sample size ($N = 128$). Although the number of participants was sufficient to obtain a desirable power level (.80) to detect relationships between variables, it remained below the ideal ratio of 20 times more research participants than independent variables suggested by Tabachnick and Fidell (1989). The ideal number of research participants would have been 140 for the regression equations. This may have been especially important for the statistical analyses conducted to test the hypothesis that coresidence status moderated the relationship between variables and SB, since the analytical procedures required that the total sample of caregivers be divided into two groups based on the coresidence status. The smallest subgroup ($n = 54$) only met the minimum requirement of 10 participant subjects to 1 variable.

The increased probability of making a Type I error given the total number of analyses conducted in the study is another concern. If Bonferroni corrections had been performed for the total number of statistical analyses conducted, the effect size required to reject a null hypothesis would have been so large that the likelihood of identifying associations between variables would have been very low. Given the exploratory nature of the present study, statistical analyses were grouped into meaningful units (i.e., correlational analyses, regression analyses evaluating the three research hypotheses, analyses testing the moderating effect of coresidence status and analyses testing the mediating effect of sense of mastery on an independent variable), and the alpha level was set at .05 for each of these units of analyses. However, the reader should keep in mind that the total number of statistical analyses conducted in this study place the overall probability of

making a Type I error above .05. Attempts to replicate these findings with other samples of caregivers would be helpful to reduce the probability of falsely identifying relationships between variables.

A fifth important limitation relates to the cross-sectional nature of the research design and the use of self-report measures. A cross sectional design doesn't provide information on the temporal order of variables. Longitudinal research designs are needed to increase our understanding of the changes in SB over time and to help identify variables predicting these changes. Studies that used longitudinal research designs showed that SB was relatively stable over time (Jones, 1996; Tessler & Gamache, 1994; Test & Stein, 1980). Seltzer et al. (1997) and Greenberg, Seltzer et al. (1997) found that burden at time 1 was a strong predictor of burden three years later. However, few symptoms of the illness, separate living arrangement between the caregiver and the care recipient and membership in a support group predicted low SB 18 months later (Greenberg, Seltzer et al.; Seltzer et al.). Hospitalization of the care recipient was also followed by a reduction in SB (Herz, Endicott & Spitzer, 1976). Furthermore, because caregiving in mental illness is a chronic stressor, it is likely that SB, over time, also influence other variables in the caregiving system. Future studies should analyze relationships between the different variables and SB using structural equation modelling techniques such as path analysis or LISREL to provide information on the direction and strength of the relationship between pairs of variables.

The use of self-report measures and its impact on the relationships between SB and other variables should also be considered when interpreting the study findings. Self-report measures involve the possibility of bias introduced by the current affective state of the respondent. For

example, a depressed mood may reduce the ability of the caregiver to perceive support offered by other family members or to experience satisfaction received from caregiving activities. Self-report measures also imply the presence of multiple rater biases. In contrast to an interview format where the bias introduced by the rater is similar between subjects, a self-report format involves the use of different raters with their own bias. The variability between subjects resulting from rater bias, an error factor, contributes to underestimate the relationship between study variables.

Directions for Future Research Work

The study findings have implications for future research work. The use of longitudinal research designs and data analysis methods which provide information on the nature and direction of relationships between variables would be most helpful in the development of appropriate theoretical frameworks for describing the experience of caregiving in mental illness. Areas highlighted in the present study findings which merit further attention from researchers include clarification of the association between SB and other variables such as adverse effects on the caregivers' lives, aspects of the relationship between the caregiver and the person with mental illness and family support. Other areas of study that have recently emerged from the caregiving literature in severe mental illness are also mentioned below.

With regard to stressor variables, the strength of association between adverse effects on the caregiver's life and SB raised concerns about the possibility of overlapping between the two constructs. Researchers should attempt to replicate these findings to determinate how the strength of the association is affected by cross-validation on other samples of caregivers and to determine if empirical findings support the differentiation of adverse effects and SB into separate constructs. Although the distinction between the two constructs is clear from a theoretical

perspective, few studies in the research literature have reported empirical findings about the relationship between them.

Researchers should also investigate the relationship between SB and the caregivers' interactions with the mental health system. To date, most sources of stress for family caregivers studied were restricted to their interactions with the person with mental illness. However, SB derives not only from the experiential aspects of living with mental illness in the family, but also from the caregivers' interactions and frustrations with the mental health system (Lefley, 1996). Deficits of the service systems (e.g., inability to hospitalize, legal constraints, premature discharge, exclusion of the person with mental illness from programs, lack of funding) as well as deficits of the clinicians (e.g., failure to include the caregiver in the treatment plan, misuse of confidentiality, inappropriate treatment plans, lack of communication between professionals, attitudinal rejection) are stressors caregivers face on a regular basis (Lefley, 1996). Although the research literature has consistently highlighted caregivers' dissatisfaction with services over the last two decades (Biegel, Li-Yu & Milligan, 1995; Grella & Grusky, 1989; Hanson & Rapp, 1992; Holden & Lewine, 1982), researchers have been slow to include these stressors in burden studies. With regard to family resource variables, future research should attempt to replicate findings of a direct association between SB and level of intimacy and conflict in the relationship between the caregiver and the person with mental illness. Future research should also attempt to evaluate other aspects of the relationship that can be easily addressed in psychological intervention such as communication and problem solving abilities, and determine how these aspects of the relationship relate to sense of mastery and to SB. An analytical framework which would help clarify associations between symptomatic behaviors of the person with mental illness, quality of the

relationship between the caregiver and the care recipient, sense of mastery and SB would be helpful to determine the nature of psychological intervention that would help to reduce burden. Furthermore, because spousal and parental relationships differ in nature, it would be interesting to determine whether kinship between the caregiver and the person with mental illness moderates the association between aspects of the relationships and other variables.

Future research should also attempt to clarify the relationship between family support and SB. Non replicated findings have identified a relationship between SB and the amount of time the caregiver spouse spent with the adult child with severe mental illness. The present study failed to show a relationship between SB and the caregiver's perception of support received from family members other than the person with mental illness. Future research should attempt to determine whether the difference in findings observed was a result of the nature of the support provided (i.e., instrumental vs. emotional), or a result of kinship between the provider of support and the caregiver (i.e., spouse vs. other relative).

With regard to appraisal variables, coping behaviors of caregivers in severe mental illness have been gaining attention in recent years. Although some of the variables that have been included in previous studies (social support, appraisal of the situation) can be conceptualized as coping, more specific behavioral strategies are starting to gain the attention of researchers (Bibou-Nakou et al., 1997; Magliano et al., 1998; Webb et al., 1998). Findings about behavioral strategies and their impact on SB have not been replicated. Researchers should attempt to replicate these findings in order to increase understanding of the ways caregivers cope with their situation. Also, given that coping styles may change overtime as the illness progresses and caregivers deal with repeated hospitalizations and symptomatic behaviors, longitudinal research

designs would again be helpful in understanding the experience of caregivers and the relationships between coping behaviors, SB and adaptation outcomes. Furthermore, in keeping with the objective of grounding the field of caregiving in mental illness in a theoretical framework, models of family response to mental illness, such as the nine-stage model of Tessler, Killian, and Gubman (1987), the evolutionary model of Terkelsen (1987), and the family recovery model of Spaniol and Zipple (1994), could be helpful in studying coping behaviors of caregivers.

Another promising area of research that includes elements of coping, cognitive appraisal as well as personal and psychological resources involves the meaning caregivers attribute to the caregiving situation. To date, very few studies have attempted to describe ways in which caregivers make sense of, or derive meaning from their role as caregivers for a relative with a mental illness. Knowledge of how caregivers derive meaning from their caregiving activities may help researchers understand factors related to sustained caregiving, and help identify effective intervention for families who struggle with caregiving (Reinhard & Horwitz, 1995). Rose (1998) conducted extensive interviews of family caregivers of psychiatric inpatients. A thematic analysis of the textual data revealed that meaning in caregiving was comprised of the following concerns: finding the essence of the person with the illness; finding a place for oneself in influencing the illness; and helping the relative to move forward. This analysis highlights themes that are related to sense of mastery, which was associated with SB in the present study. Meaning in caregiving for the older person was also studied by Farran, Keane-Hagerty, Salloway, Kupferer and Wilken (1991). They identified major existential themes in caregiving, and Farran and colleagues recently developed a measurement instrument for meaning in caregiving (Farran, Miller, Kaufman, Donner, & Fogg, 1999).

Finally, study findings in the research literature suggest that some characteristics of caregivers affect the relationship between SB and other variables. Non-replicated findings showed that different variables explained variability in SB for male and female caregivers (Noh & Avison, 1988), and for sibling and parent caregivers (Horwitz & Reinhard, 1995). In the present study, findings suggest that the strength of the relationship between sense of mastery and SB is affected by coresidence status between the caregiver and the person with mental illness. Future studies should analyze findings on different groups of caregivers, in order to identify variables that moderate the relationship between SB and other variables.

Implications for Clinical Practice

Given the direct association of caregivers' SB with the presence of symptomatic behaviors in the person with mental illness and sense of mastery in caregiving, clinical interventions focusing on improving caregivers' skills in dealing with symptomatic behaviors should contribute to reducing their feelings of SB. Participation in a psycho-educational group about caregiving in severe mental illness which provides information about the illness and which suggests adaptive coping behaviors to difficulties encountered in caregiving should therefore reduce SB. Participation in such a group would be especially beneficial for caregivers maintaining separate living arrangements with care recipients, given the stronger association between sense of mastery and SB for that group of caregivers. In addition, because SB is also directly related to caregivers' depressive symptoms and satisfaction with life, participation in a psycho-educational group should contribute to improve caregivers' overall sense of psychological well-being by decreasing depressive symptoms and increasing satisfaction with life.

Clinical interventions designed to provide respite and instrumental help to caregivers,

which has been found effective for people caring for an older person with cognitive impairment (Aneshensel et al., 1995), have not been implemented on a large scale with caregivers for persons with severe mental illness. Given the strong correlation between adverse effects on the caregiver's life and caregivers' SB, respite care and instrumental help would probably be helpful in reducing the amount of adverse effects on the caregiver's life and therefore reducing SB and improving well-being. Associations such as the Schizophrenia Society or the Association for People Suffering from Depression and Manic Depression, as well as treatment facilities and the Internet are usually helpful in informing caregivers about available services in their geographic area. These services may include day care, respite care services, companion services, transportation, home health aides, home maker services and home delivered meals.

In addition, the indirect association between SB and the quality of the relationship between the caregiver and the person with mental illness suggest that interventions designed to improve the relationship would contribute to increase sense of mastery and reduce SB. In a recent meta-analysis of the effects of family interventions on relatives' burden, Cuijpers (1999) found that family interventions, especially those involving 12 or more sessions, had positive effects on relatives' burden, psychological distress, the relationship between the family member and the person with mental illness, and family functioning. Interventions targeting the relationship between the caregiver and the care recipient should therefore be included in treatment plans and offered to caregivers, to reduce the impact of their involvement in caregiving.

Finally, the indirect association between satisfaction received from caregiving activities and SB also has implications for psychological interventions. Study findings suggest the possibility that interventions designed to modify caregivers' cognitions by helping them recognize

positive aspects of caregiving may contribute to increasing their sense of mastery, which in turn may result in reduced SB. Psychological interventions using a cognitive approach would most likely be helpful in reducing SB in caregivers.

Marsh and Johnson (1997) identified essential needs characteristic of families coping with a relative's mental illness and suggested psychological interventions with families that were likely to address these needs. The psychological interventions they suggested included: (1) understanding and normalizing families' experience in mental illness; (2) focusing on the strengths and competencies of the families; (3) learning about mental illness, the mental health system and community resources; (4) developing skills in stress management, problem solving and communication; (5) resolving feelings of grief and loss; (6) coping with symptoms of mental illness and their repercussions on the family; (7) identifying and responding to signs of impending relapse; (8) creating a supportive family environment; (9) developing realistic expectations for all members of the family; (10) playing a meaningful role in their relative's treatment, rehabilitation and recovery; and (11) maintaining a balance that meets the needs of all members of the family. Whereas interventions #3, #4, #6 and #7 can be provided through psycho-educational and support groups, mental health professionals can offer the remaining interventions by adopting a supportive attitude towards caregivers and their families and by using a cognitive behavioral approach in helping caregivers coping with the demands of caring for a relative or a close friend suffering from severe mental illness. In a recent study by Bland and Harrison (2000) on the development and evaluation of a psycho-education program for caregivers of individuals with bipolar affective disorder, timing of the intervention was another important factor mentioned. They suggested that a psycho-education program might be most beneficial at the time where the caregiver is

experiencing high levels of distress. This implies that the intervention protocol should be flexible enough to allow entry in the program at any given time.

Conclusion

Some important conclusions emerged from the study findings:

- (1) The present study findings showed that symptomatic behaviors of the person with mental illness and sense of mastery in caregiving activities predicted SB. These findings were consistent with those reported in the research literature of caregiving for people with a severe mental illness.
- (2) Study findings also showed that SB predicted depressive symptoms in caregivers and caregivers' satisfaction with life. The prediction of depressive symptoms by SB was consistent with findings reported in the research literature in caregiving for people with severe mental illness. The prediction of satisfaction with life by SB is an original contribution to the research literature in caregiving for people with severe mental illness. The relationship between these two variables was previously found for caregivers for older persons with cognitive impairment.
- (3) Quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities both predicted sense of mastery, which in turn predicted SB. Sense of mastery therefore mediated the association between SB and the two independent variables (i.e., quality of the relationship between the caregiver and the person with mental illness and satisfaction received from caregiving activities). These findings were observed for the whole group of caregivers and for caregivers maintaining separate living arrangements with the care recipient.
- (4) Coresidence status moderated the relationship between sense of mastery and SB. For caregivers who maintained separate living arrangements with the care recipient, sense of mastery

had a stronger negative association with SB than for caregivers who resided with the care recipient.

(5) The strength of association between adverse effects on the caregiver's life and SB was such that it raised concerns about the possibility of overlapping between the two constructs. Although the distinction between the two constructs is clear from a theoretical perspective, findings of the present study could not differentiate them as separate constructs.

(6) Findings were consistent with a stress and coping framework, where social and psychological resources moderate or mediate the relationship between stressors and adaptation outcomes.

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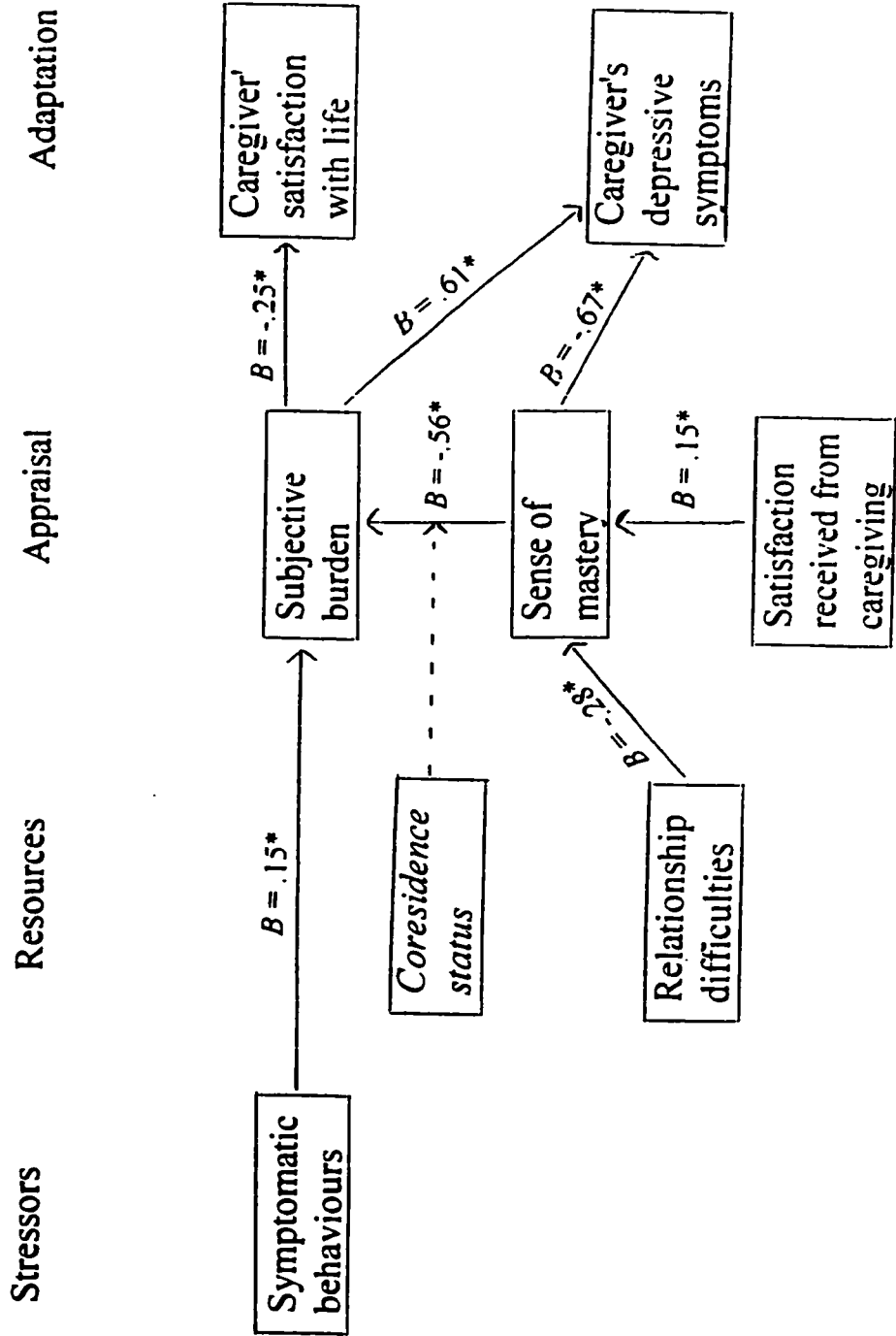


Figure 1. Path diagram of the significant relationships identified by study findings.
 Note. * = $p < .05$. A dashed line indicates a moderating effect.

Table 1

Research Designs and Major Findings of Studies About Caregiver Burden in Mental Illness

Source	Research design and sampling	Variables included in studies	Major findings
Bibou-Nakou, Dikaiou, & Bairactaris (1997)	Cross sectional, N = 52. Respondents were primary caregivers and resided with the care recipients. Correlational statistics were used.	Variables were caregivers' level of distress, feelings of mastery, coping strategies (good/ warm style, critical, overinvolved, variable and passive), OB and SB.	OB was correlated with caregivers' distress and feelings of mastery, but was not correlated with coping strategies. SB was correlated with caregivers' distress and the use of a good/ warm style of coping strategies.
Biegel, Milligan, Putnam, & Sung. (1994)	Cross sectional, N = 103. Respondents were primary caregivers. Care recipients agreed to have their caregivers contacted. Half of caregivers resided with the care recipients. Regression statistics were used.	IVs were symptomatic behaviors, number of times clients returned home after hospitalization, social support, family support, professional support and caregivers' health. DVs were overall burden, family disruptions (OB) and stigma (SB).	Care recipients' behaviors and lack of perceived support from family members were associated with overall burden, whereas professional and social support were not associated with it. Care recipients' behaviors, number of times they returned home after hospitalization, the absence of professional support, and caregivers' health were associated with family disruptions (OB), whereas social support was not associated with it. Care recipients' behaviors and the absence of family support were associated with stigma (SB).
Bulger, Wandersman, & Goldman. (1993)	Cross sectional, N = 60. Respondents were primary caregivers of an adult child with mental illness. One third were directly contacted in support groups. Sixty percent resided with the adult child. Regression statistics were used.	IVs were symptomatic behaviors, intimacy and conflicts in the relationship with the ill relative. DV was overall burden.	Symptomatic behaviors and the absence of a good relationship with the ill relative, as measured by intimacy and conflicts, were associated with overall burden in caregivers.

Source	Research design and sampling	Variables included in studies	Major findings
Clark. (1994)	Cross sectional, matched control group design, N = 246 (n1 = 119, n2 = 127). n1 group had severe mental illness and substance abuse. n2 group consisted of healthy community residents. Respondents were parents, and 26% resided with their adult child. Regression statistics and t-tests were used.	IVs were clients' age and gender, illness condition and family income. DVs were the amount of caregiving activities performed (OB) and equivalent economical value including financial help (OB).	Using the Opportunity-cost method for valuing family time, families in the dual disorder group gave \$4,301 worth of care per year, while families in the community group gave \$1,689. The Substitution-cost method yielded respective yearly estimates of \$9,703 and \$2,421. The variable most highly associated with the amount of caregiving activities performed was the illness condition. Income was associated with the amount of financial help provided to the child for community families, but not for families with a ill child. Clients' age and gender were not associated with caregiving activities or financial help.
Cook, Lefley, Pickett, & Cohler. (1994)	Cross sectional, N = 222. Caregivers were parents of 134 offsprings beginning treatment at a psychiatric rehabilitation agency. Regression statistics were used.	IVs were caregivers' age, gender, ethnicity and education, clients' gender, level of functioning and number of years of illness, and caregivers' psychological adjustment. DVs were feelings of ongoing responsibility for the ill child (SB) and management of disruptive behaviors (SB).	Being older, reporting lower levels of psychological adjustment, belonging to an ethnic minority, having few years of formal education, a higher level of functioning in the client and recency of illness were associated with higher levels of burden related to feelings of ongoing responsibility for the ill child (SB). Being younger, reporting lower levels of psychological adjustment, being White, the client being a woman and having been ill for a longer time were associated with higher levels of burden related to management of their offsprings' behaviors (SB).
Cornwall, & Scott. (1996)	Longitudinal (6 months), N = 37. Respondents were identified by care recipients as "the most significant other person". Descriptive and correlational statistics were used.	Variables were OB (at times 1 and 2), SB (at times 1 and 2), care recipients' level of functioning (at time 1), caregivers' satisfaction with services (at times 1 and 2), and caregivers' distress (at times 1 and 2).	Levels of OB and SB decreased significantly over the six-month period (acute phase of illness to follow-up). During the acute phase (time 1), OB and SB were negatively correlated with the care recipients' level of functioning. OB was positively correlated with SB. At six-month follow-up (time 2), OB and SB were positively correlated with caregivers' distress. SB was also negatively correlated with caregivers' satisfaction with services.

Source	Research design and sampling	Variables included in studies	Major findings
Creer, Sturt, & Wykes. (1982)	Cross sectional, N = 52. Forty-five percent of respondents resided with the care recipients. Descriptive statistics were used.	Variables were OB and SB in assistance in daily living and supervision.	Prevalence of support provided was similar in areas of assistance with self care and supervision of difficult behaviors. Areas needing more assistance were managing money (57%) and doing housework (52%). Much supervision was provided because the ill relative could not be left alone (63%). In other areas, prevalence of OB reported ranged from 15% to 30%.
Crotty, & Kulys. (1986)	Cross sectional, N = 56. Care recipients of an outpatient community mental health facility identified a family member or friend. Descriptive and correlational statistics were used.	IVs were clients' age, gender, education, coresidence, number of people in the household, number of psychiatric hospitalizations, recency of last hospitalization and clients' social support. DV was overall burden.	Respondents reported mild to moderate levels of overall burden. No demographic or illness related variables studied were significantly correlated with family burden. Having few members in the household and significant others' perception that care recipients received social support were correlated with low levels of burden.
Gibbons, Horn, Powell, & Gibbons. (1984)	Cross sectional, N = 163. Respondents were caregivers of clients who had used psychiatric services in the previous year, and were contacted without the care recipients' prior consent. Descriptive statistics were used.	IVs were clients' age and gender, kinship with the ill relative, coresidence, symptomatic behaviors and years of illness. DVs were OB, SB and overall burden.	Over 70% of care recipients presented disruptive behaviors, impaired social performance, and caused family hardships. Reported levels of OB and SB were similar for care recipients' social performance, but levels of SB reported were larger than associated OB for care recipients' behaviors and family hardships. Higher levels of overall burden were reported for younger clients, for those whose illness was recent and for those who presented symptomatic behaviors.

Source	Research design and sampling	Variables included in studies	Major findings
Greenberg Seltzer, Krauss, & Kim. (1997)	Longitudinal (3 years), N = 361. Between group design (n1 = 73, n2 = 288). n1 group were aging mothers (55 and over) caring for an adult child with severe mental illness. n2 group were aging mothers caring for an adult child with mental retardation. All caregivers resided with the care recipient. Regression statistics were used.	IV were measured at time 1 and included, amount of care provided, behavioural problems, pessimism about the future, size of social network, being a member of a support group and number of close friends in network who also cared for a ill relative. IVs also included SB at time 1 and residential status at time 2. DV was SB at time 2.	With regard to caregivers of a mentally ill child, caregivers' high level of SB at time 1, not being a member of a support group and not having a large number of close friends who also cared for a relative with mental illness explained 50% of the variability in SB at time 2.
Greenberg Kim, & Greenley. (1997)	Cross sectional, N = 164. Respondents were siblings and primary caregivers of care recipients. Mental health professionals asked care recipients to identify caregivers. Regression statistics were used.	IVs were caregivers' age, gender, education, health and birth position, care recipients' gender and diagnosis, amount of care, psychiatric symptoms, and control attribution (perceiving care recipients' behaviours as being under their control). DVs were overall SB, stigma (SB), fears (SB) and worries (SB).	Being highly educated psychiatric symptoms and control attribution explained 22% of the variance in overall SB. Being young caregiver, caring for a ill relative with schizophrenia, psychiatric symptoms and the interaction of symptoms and attribution of control explained 32% of the variance in stigma (SB). Being young caregiver, being less involved in providing care, psychiatric symptoms and control attribution explained 37% of the variance in fears (SB). Psychiatric symptoms and control attribution explained 18% of the variance in worries (SB).
Hatfield. (1978)	Cross sectional, N = 89. Family members were recruited directly through self-help groups. Fifty-seven percent of respondents resided with care recipients. Descriptive statistics were used.	OB and SB were reported for different aspects of caregiving in mental illness.	Highest OB was reported for hardships caused to other family members, disruption in social life and in the personal life of other family members. Highest SB was reported for low levels of care recipients' functioning, night disturbances, odd or unusual speech or ideas, and uncooperativeness.

Source	Research design and sampling	Variables included in studies	Major findings
Herz, Endicott, & Spitzer. (1976)	Longitudinal (3 months), N = 153. Respondents were family members of care recipients recently admitted to an inpatient setting. Descriptive and correlational statistics were used.	OB and SB were reported for different aspects related to caregiving in mental illness.	Prevalence of OB was highest for financial problems due to the illness, assuming care recipients' responsibilities, amount of time spent in caregiving, care recipients' symptomatic behaviors and missed work. Prevalence of SB was highest for worrying about the future, being distressed, being careful not to upset care recipients and night disturbances. Correlations between care recipients' symptomatology and OB were higher than those between symptomatology and SB.
Hoenig, & Hamilton. (1966)	Cross sectional, N = 62. Respondents were family members residing with the care recipient. Descriptive statistics were used.	IVs were care recipients' gender and age, and duration of illness. DVs were SB and aspects of OB.	Prevalence of OB was reported for disturbing behaviors and adverse effects on the household. Most disturbing behaviors (OB) were odd speech or unusual ideas, uncooperativeness, being dangerous to themselves or to others, and night disturbances. Most adverse effects on the household (OB) included disruptions in life routine, financial problems, health problems and effects on household children.
Horwitz, & Reinhard. (1995)	Cross sectional, N = 148. Respondents were parents (78) and siblings (70) of clients facing discharge from hospital. They were approached without clients' prior consent. Regression statistics and t-tests were used.	IVs were caregivers' age, gender, ethnicity, income, coresidence and kinship with the ill relative, involvement in caregiving duties, diagnosis and stigma. DV was overall burden in parents and siblings	Black and White parents reported similar levels of caregiving involvement, but White parents reported more overall burden. Black siblings reported more caregiving involvement than White siblings, but less burden. Being White, young, highly involved with caregiving duties and experiencing stigma were associated with high parental burden. Being White, highly involved with caregiving duties and experiencing stigma were associated with high burden in siblings.
Jones. (1996)	Longitudinal (3 years), N = 168. Care recipients were asked to identify a family member or friend. Descriptive and correlational statistics were used.	Variables were OB and SB.	OB related to assistance was more intense than OB for supervision. Assistance OB was systematically higher than assistance SB, whereas reported levels of OB and SB for supervision were similar. Results were consistent over the three years. Correlations between OB and SB were moderate to high.

Source	Research design and sampling	Variables included in studies	Major findings
Jones, & Jones. (1994)	Cross sectional, N = 189. Care recipients were asked to identify a family member or friend. Descriptive statistics were used.	Variables were OB and SB in assistance in daily living (grooming, medication, housework, shopping, cooking, transportation, children and time and money management) and supervision (embarrassment, excessive demands, kept up at night, violence, suicide, alcohol and drug abuse).	Prevalence of SB is lower than OB for assistance in daily living, but SB is higher than OB for supervision. Largest discrepancies between OB and SB (OB higher than SB) were reported for assistance in areas of transportation, taking care of clients' children, managing money and helping with medication. Largest discrepancies for supervision (SB higher than OB) occurred in areas of embarrassing behaviors, violent behaviors, suicide attempts and use of illegal drugs.
Jones, Roth, & Jones. (1995)	Cross sectional, N = 189. Clients identified a family member or friend. Thirty-six percent of respondents resided with the care recipients. Regression statistics were used.	IVs were caregivers' age, gender and ethnicity, clients' age and gender, and coresidence. DVs were assistance in daily living (OB), supervision (OB), assistance in daily living (SB) and supervision (SB).	OB for assistance in daily living was associated with coresidence and clients' old age. OB for supervision was associated with coresidence and clients being men. SB for assistance in daily living was associated with coresidence, clients' young age (money management and caring for clients' children), and clients being women (caring for clients' children). None of the variables were associated with SB for supervision.
Lefley. (1987b)	Cross sectional, N = 84. Caregivers responded to posted solicitations asking for mental health professionals with family members with mental illness. Descriptive statistics were used.	SB was reported for different aspects related to caregiving in mental illness.	Ninety-one percent of caregivers contributed financially to the care of their care recipients, with an average of \$44,000 by family. Seventeen percent to 95% of caregivers reported SB resulting from their care recipients' behaviors. Most disturbing behaviors reported were mood swings (95%), disruption of household routines (85%), social isolation (84%) and lack of motivation (83%).

Source	Research design and sampling	Variables included in studies	Major findings
Magliano, Fadden, Madianos, Caldas de Almeida, Held, Guarneri, Marasco, Tosini, & Maj. (1998)	Cross sectional, N = 236. Respondents were primary caregivers and resided with the care recipients. Care recipients agreed to have their caregivers contacted. Regression statistics were used.	IVs included coping strategies (coercion, avoidance, social involvement of the ill relative, information, maintenance of social interests, talking with friends, use of alcohol, resignation) and social and professional resources (emotional support, practical support, professional help, understanding by friends). DV's were OB and SB.	Caregivers' OB was associated with coping strategies (social involvement of the ill relative, positive communication, avoidance, seeking for information, maintenance of social interests, talking with friends, resignation) and resources (practical support). SB was associated with coping strategies (avoidance, maintenance of social interests, talking with friends, resignation, spiritual help, use of alcohol), but was not associated with social or professional resources.
Noh, & Avison. (1988)	Cross sectional, N = 163. Care recipients were spouses of caregivers, resided with them and gave prior consent. Regression statistics were used.	IVs were caregivers' age, gender and education, symptomatic behaviors, community tenure, diagnosis, client employed, caregiver employed, family income, children in the home, caregivers' stressful life events, social support and sense of mastery. DV was overall SB.	Care recipients' symptoms, presence of stressful life events and sense of mastery were associated with SB in spouse caregivers. Results computed separately for male and female caregivers presented different patterns. Care recipients' symptoms, community tenure and stressful life events were associated with SB for male caregivers. Old age, low mastery and presence of other children in the household were associated with SB in female caregivers.

Source	Research design and sampling	Variables included in studies	Major findings
Pickett, Greenley, & Greenberg (1995)	Cross sectional, N = 436. Respondents were parents of an adult child with mental illness. Twenty percent of respondents resided with their adult child. Regression statistics were used.	IVs were caregivers' age, gender, education and marital status, care recipients' gender, psychiatric symptoms, functioning, amount of care, number of psychiatric hospitalizations, coresidence, supervised housing, care recipients' employment status, competitive employment, current marital status, have children, ever married, education and off-timedness. DVs were caregivers' losses (OB), worries (SB), fears (SB) and stigma (SB).	Caregivers' young age, being highly educated, psychiatric symptoms, amount of care provided, residing with the ill child and the ill child being unemployed explained 29% of the variance in caregivers' losses (OB) due to the illness. Psychiatric symptoms, number of psychiatric hospitalizations, amount of care provided, the ill relative not being employed and off-timedness in meeting normative goals explained 25% of the variance in worries (SB). Caregivers' young age, psychiatric symptoms, residing with the ill child, the ill child remaining single and off-timedness in meeting normative life goals explained 46% of the variance in fears (SB). Caregivers' young age and clients' psychiatric symptoms explained 14% of the variance in stigma (SB).
Pickett, Vraniak, Cook, & Cohler. (1993)	Cross sectional, N = 209. Respondents were parents of an adult child with mental illness who attended a psychosocial rehabilitation program. Half of the respondents lived with their adult child. Correlational statistics were used.	IVs included single and combined variables. Single variables were caregivers' ethnicity and depression, clients' behavior-age discrepancy, immaturity and lack of motivation. Combined variables were (education, income), (number of years ill, number of hospitalizations), and measures of potential social support. DVs were feelings of responsibility for the client (SB) and management of disruptive behaviors (SB).	For White parents, low education and income, depressive symptomatology and client's immaturity were positively associated with feelings of ongoing responsibility for the ill child (SB). Also for White parents, number of lifetime hospitalizations and length of illness, depressive symptomatology, ill child's behavior-age discrepancy in behaviors, lack of motivation and immaturity were positively associated with management of the child's behaviors (SB). For Black parents, depressive symptomatology was positively associated with feelings of ongoing responsibility for the ill child (SB), whereas potential social support resources, behavior-age discrepancy and lack of motivation were positively associated with management of the child's behaviors (SB).

Source	Research design and sampling	Variables included in studies	Major findings
Potasznik, & Nelson. (1984)	Cross sectional, N = 56. Caregivers were parents of an adult child with mental illness. They were members of self-help groups, and were directly contacted. Forty-six percent lived with their adult child. Regression statistics were used.	IVs were clients' symptomatology, caregivers' satisfaction with social network and supportiveness of self-help group. DVs were OB and SB.	Psychiatric symptomatology in clients was positively associated with OB and SB in caregivers. Supportiveness of a self-help group was negatively associated with OB.
Provencher, & Mueser. (1997)	Cross sectional, N = 70. Respondents were primary caregivers, and were contacted directly through self-help groups. Sixty-five percent lived with the care recipients. Correlational statistics were used.	IVs were care recipients' positive and negative symptom behaviors, and responsibility attribution associated with these symptoms. DVs were OB and SB.	OB was positively related to the severity of negative symptom behaviors and to caregivers' perception of the care recipients' responsibility for negative symptoms. OB was not related to positive symptom behaviors or responsibility attribution for positive symptoms. SB was positively associated with both the severity of positive and negative symptom behaviors, but it was not related to responsibility attribution.
Reinhard. (1994)	Cross sectional, N = 94. Respondents were primary caregivers of the care recipients. Thirty-six percent of respondents lived with the care recipients. Regression statistics were used.	IVs were caregivers' age, gender, education and income, clients' symptomatic behaviors, caregivers' sense of personal control and professional support. DVs were OB and overall burden.	OB was positively associated with the care recipients' symptomatic behaviors, and negatively associated with caregivers' sense of personal control and professional support (practical advice). Socio-demographic variables included in the study were not associated with OB. Symptomatic behaviors were associated with feelings of overall burden.
Seltzer, Greenberg Krauss, & Hong. (1997)	Longitudinal (3 years), N = 361. Between group design (n1 = 73, n2 = 288). Caregivers were aging mothers caring for an adult child with severe mental illness (n1) or with mental retardation (n2). All caregivers resided with their adult child. Regression statistics were used.	IV's were SB at time 1, client's gender, caregivers' age, marital status, health and size of support network, amount of care provided, behavioural problems, caregivers' venting of emotions, and residential status at time 2. DV was SB at time 2.	Caregivers' SB at time 1 and coresidence status at time 2 explained 55% of the variability in SB at time 2.

Source	Research design and sampling	Variables included in studies	Major findings
Solomon, & Draine. (1995)	Cross sectional, N = 225. Respondents were primary caregivers of the care recipients, and were contacted without the care recipients' prior consent. Forty-five percent of respondents lived with the care recipients. Regression statistics were used.	IVs were caregivers' age, gender, ethnicity, education, income and kinship with the ill relative, schizophrenia diagnosis in clients, above-median life-time hospitalizations, level of functioning, years of illness, current crisis, coresidence, caregivers' social support, support group, self-efficacy, mastery and satisfaction with coping responses. DV was overall SB.	Not living with the ill relative, high levels of social support, self-efficacy and mastery, and being satisfied with one's coping responses explained 39% of the variance in SB. Socio-demographic variables, illness-related stressors and belonging to a support group were not associated with feelings of SB.
Song, Biegel, & Milligan. (1997)	Cross sectional, N = 103. Respondents were primary caregivers, and were contacted with the care recipients' prior consent. Fifty-three percent of respondents lived with the care recipients. Regression statistics were used.	IVs were caregivers' gender, ethnicity, coresidence, care recipients' disruptive behaviors, caregivers' social support, sufficiency of family support, sufficiency of agency support and caregivers' health. DV was overall SB.	The absence of disruptive behaviors, perceived sufficiency of family support and perceived sufficiency of agency support were negatively associated with SB. Caregivers' gender, ethnicity, coresidence, social support and caregivers' health were not associated with SB.
Stueve, Vine, & Struening. (1997)	Cross sectional, N = 180. Respondents were primary caregivers of care recipients recently admitted to a psychiatric inpatient setting. Thirty-eight percent of caregivers lived with the care recipients. Regression statistics were used.	IVs were caregivers' ethnicity, age gender, education, income and kinship with client, clients' psychiatric symptoms, amount of care, amount of social support, quality of social support, church attendance, importance of religion, medical model index, and devaluation/ stigma for family and ill relative. DV was overall burden.	Caregivers' young age, being White or Hispanic, clients' psychiatric symptoms, amount of care provided and perceived quality of social network explained 34% of the variance in overall burden. Burden was not associated with caregivers' gender, education, income, kinship with the care recipient, amount of social support, religious involvement and illness attribution variables.

Source	Research design and sampling	Variables included in studies	Major findings
Tessler, & Gamache. (1994)	Longitudinal (3 years), N = 305. Clients of psychiatric hospital and 24 hr crisis facilities (175) identified 305 family members or friends. Seventeen percent of respondents resided with caregivers. Regression statistics were used.	IVs were coresidence, kinship with the care recipient (being a parent, being a primary kin other than parent), and receiving continuity of care services. DVs were assistance in daily living (OB), supervision (OB) and worry (SB).	Residing with the care recipient, being a parent and the ill member receiving continuity of care services under the condition of shared residence were associated with OB in both assistance and supervision. Being a primary kin other than parent was also associated with OB in supervision. Being a parent was associated with worry (SB). No consistent pattern of variation in burden was observed over the three years.
Test, & Stein. (1980)	Longitudinal (3 months), N = 24. Respondents were family members of care recipients. Descriptive statistics were used.	Variable was OB for different aspects of household disruptions.	Prevalence of OB was highest for disruptions in social or leisure time, work missed and disruptions in domestic routine.
Thompson & Doll. (1982)	Cross sectional, N = 125. Respondents (relatives identified on the hospital form) of persons with mental illness discharged from hospital were directly contacted. They resided with the care recipients. Descriptive and correlational statistics were used.	IVs were caregivers' age, gender, ethnicity, education, income, clients' age and gender, psychological closeness between caregiver and client, symptomatic behaviors and caregivers' prediction of next hospitalization. DVs were overall OB and SB.	The incidence of OB and SB were similar. However, the proportion of families with severe OB was twice that of families with severe SB. OB and SB shared just 7% of common variance. Both OB and SB were correlated with care recipients' symptoms. SB was also correlated with caregivers' prediction that their kin would re-enter hospital in the near future, whereas OB (financial burden) was also correlated with low income.
Webb, Pfeiffer, Mueser, Gladis, Mensch, DeGirolamo, & Levinson. (1998)	Cross sectional, N = 84. Half of respondents resided with the care recipients. Some of the respondents appear to have been recruited without care recipients' prior consent. Regression statistics were used.	IV's were caregivers' age and gender, client's diagnosis, social support, positive and negative symptoms, appraisal of symptoms (changeability and acceptance) and coping strategies with symptoms (problem focused and emotion focused). DV was SB.	High levels of SB was associated with frequency of positive and negative symptoms, and the absence of problem focused coping with these symptoms. It was not associated with caregivers' age, gender, care recipients' diagnosis, social support, appraisal of symptoms and emotion focused coping.

Note. DV = dependent variable; IV = independent variable; OB = objective burden; SB = subjective burden.

Table 2

Summary of Variables Associated with Burden

Variables	Burden Dimensions					
	global OB	worry SB	stigma SB	fears SB	global SB	global burden
Socio demographic						
age of caregiver		0	-	-	0	-
gender of caregiver (female)	0	0	0	0	0	0
ethnicity (being White)					0	+
education of caregiver	0		0	0	0	0
family income	0				0	0
residing with the care recipient	+	0			+	
kinship ties (parent)						0
gender of care recipient (female)	0	0	0	0	0	
Illness-related						
symptomatic behaviors	+	+	+	+	+	+
involvement in caregiving		+	0	0		+
diagnosis					0	
Caregiver support						
social support	0				mix	mix
professional support	-					0
self-help group support					mix	
Caregiver appraisal and adaptation						
sense of mastery					-	
caregivers' health					0	

Note. - = negative association; + = positive association; mix = mixed findings; 0 = no relationship; empty cell = absence of replicated findings on the specific relationship; OB = objective burden; SB = subjective burden.

Table 3

Cronbach's Alpha Coefficients of the Different Measures Used in the Present Study.

Measures (Variables)	Cronbach's Alpha Coefficients
Burden Assessment Scale – Objective part (Adverse effects in the caregivers' life)	.88
Burden Assessment Scale – Subjective part (Subjective burden)	.81
Care Work Satisfaction Scale (Satisfaction received from caregiving activities)	.95
Centre for Epidemiologic Studies Depression Scale (Caregivers' depressive symptoms)	.90
Mastery Scale (Sense of mastery in caregiving)	.75
McMaster Family Assessment Device – General Functioning subscale (Quality of the relationship between the caregiver and the care recipient)	.87
Perceived Social Support from Family Scale (Family support)	.91
Satisfaction With Life Scale (Caregivers' satisfaction with life)	.90
Social Behavioural Assessment Schedule (Symptomatic behaviours of the person with mental illness)	.89

Table 4

Socio-Demographic Information and Descriptive Statistics of Caregivers (*N* = 128)

Variables	M	SD	%
Coreidence status (% residing with the care recipient)			57.8
Caregiver gender (% female)			71.9
Caregiver ethnicity (% caucasian)			96.1
Caregiver is a parent			52.3
Caregiver is a spouse			23.4
Caregiver is another family member			15.7
Caregiver is a close friend			8.6
Caregiver age	50.4	13.9	
Caregiver education (# of years of formal education)	13.5	3.0	
Family income	\$40,500	\$20,000	
# of weekly hours of care*	12.9	13.7	
Symptomatic behaviors of the care recipient	15.5	7.8	
Adverse effects on the caregiver's life	23.9	7.4	
Relationship difficulties between caregiver and care recipient	26.7	6.1	
Family support	13.6	5.1	
Sense of mastery in caregiving	17.7	3.5	
Satisfaction received from caregiving activities	25.7	8.8	
Subjective burden	20.8	5.6	
Caregiver' satisfaction with life	19.6	7.0	

Variables	M	SD	%
Caregiver's depressive symptoms	13.6	9.4	

Note. * = applied to caregivers who were not residing with the care recipient ($n = 54$); M = mean; SD = standard deviation; % = percentage.

Table 5

Correlation Matrix of all Variables Included in The Caregiver Burden Model

	1	2	3	4	5	6	7	8	9
1- Caregiver resides with the person with a mental illness									
2- Symptomatic behaviors of the care recipient	-.01								
3- Adverse effects on the caregivers' life	.15	.44*							
4- Relationship difficulties between caregiver and client	-.10	.44*	.28*						
5- Family support	-.06	-.27	-.22	-.20					
6- Sense of mastery in caregiving	-.03	-.31*	-.39*	-.49*	.29*				
7- Satisfaction received from caregiving activities	.06	-.31*	-.29*	-.48*	.16	.38*			
8- Subjective burden	-.05	.36*	.69*	.37*	-.10	-.46*	-.33*		
9- Caregiver' satisfaction with life	.01	-.17	-.39*	-.34*	.25	.39*	.37*	-.39*	
10- Caregiver's depressive symptoms	.09	.36*	.50*	.27	-.14	-.42*	-.12	.49*	-.40*

Note. $N = 128$. Spearman rho correlation coefficients were computed between the dichotomous variable (variable #1) and continuous variables (variables #2 to #10). Pearson correlation coefficients were computed between continuous variables.

* = $p < .001$. Because of the large number of correlation coefficients computed, Bonferroni corrections were performed to keep overall alpha level to .05. Level of significance for each correlation coefficient was therefore .001.

Table 6

Summary of Standard Multiple Regression Analysis for Variables Predicting Subjective Burden in Caregivers ($N = 128$)

Variables	B	SE B	Beta
(constant)	27.89	4.71	
Residing with care recipient	- .48	.88	- .04
Symptomatic behaviours	.15	.06	.21*
Relationship difficulties	.06	.09	.06
Family support	.09	.09	.08
Sense of mastery in caregiving	- .56	.15	- .35*
Satisfaction in caregiving	- .08	.06	- .12

Note. Adj. $R^2 = .26$. Bonferroni corrections were performed to keep overall alpha level for the three regression analyses at .05; * $p < .017$.

Table 7

Summary of Standard Multiple Regression Analysis for Variables Predicting Depressive Symptoms in Caregivers ($N = 128$)

Variables	B	SE B	Beta
(constant)	3.50	8.61	
Residing with care recipient	1.90	1.42	.10
Symptomatic behaviours	.241	.10	.20
Relationship difficulties	.01	.15	.00
Family support	.02	.15	.01
Sense of mastery in caregiving	- .67	.25	-.25*
Satisfaction in caregiving	.16	.09	.15
Subjective Burden	.61	.15	.36*

Note. Adj. $R^2 = .31$. Bonferroni corrections were performed to keep overall alpha level for the three regression equations at .05; * $p < .017$.

Table 8

Summary of Standard Multiple Regression Analysis for Variables Predicting Satisfaction with Life in Caregivers ($N = 128$)

Variables	B	SE B	Beta
(constant)	15.54	6.72	
Residing with care recipient	- .14	1.11	- .01
Symptomatic behaviours	.10	.08	.12
Relationship difficulties	- .12	.12	- .10
Family support	.22	.11	.16
Sense of mastery in caregiving	.29	.20	.14
Satisfaction in caregiving	.16	.07	.20
Subjective Burden	- .31	.11	- .25*

Note. Adj. $R^2 = .24$. Bonferroni corrections were performed to keep overall alpha level for the three regression equations at .05; * $p < .017$.

Table 9

Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Subjective Burden in Caregivers (N = 128)

Variables	B	SE B	Beta
model 1			
(constant)	21.17	.77	
Residing with care recipient	-.59	1.01	-.05
model 2			
(constant)	17.13	1.18	
Residing with care recipient	-.55	.95	-.05
Symptomatic behaviours	.26	.06	.36*
model 3			
(constant)	11.66	2.81	
Residing with care recipient	-.27	.93	-.02
Symptomatic behaviours	.18	.07	.25*
Relationship difficulties	.24	.09	.26*
Family support	.01	.09	.01
model 4			
(constant)	27.89	4.71	
Residing with care recipient	-.48	.88	-.04
Symptomatic behaviours	.15	.06	.21*
Relationship difficulties	.06	.09	.06
Family support	.09	.09	.08
Sense of mastery in caregiving	-.56	.15	-.35*
Satisfaction in caregiving	.16	.09	.15
Sense of mastery in caregiving	-.07	.06	-.12

Note. Adj. $R^2 = .00$ for model 1. Adj. $R^2 = .12$ for model 2. Adj. $R^2 = .16$ for model 3. Adj. $R^2 = .26$ for model 4. Bonferroni corrections were performed to keep overall alpha level for the three regression equations at .05; * $p < .017$.

Table 10

Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Satisfaction with Life in Caregivers ($N = 128$)

Variables	B	SE B	Beta
model 1			
(constant)	19.54	.96	
Residing with care recipient	.15	1.26	.01
model 2			
(constant)	21.89	1.56	
Residing with care recipient	.12	1.25	.01
Symptomatic behaviours	- .15	.08	-.17
model 3			
(constant)	25.36	3.58	
Residing with care recipient	- .12	1.19	-.01
Symptomatic behaviours	.02	.09	.02
Relationship difficulties	- .36	.11	-.31*
Family support	.27	.12	.19
model 4			
(constant)	6.88	6.07	
Residing with care recipient	.01	1.14	.00
Symptomatic behaviours	.06	.08	.06
Relationship difficulties	- .14	.12	-.12
Family support	.20	.12	.14
Sense of mastery in caregiving	.46	.19	.23
Satisfaction in caregiving	.18	.07	.23*

Table 10 (continued)

Variables	B	SE B	Beta
model 5			
(constant)	15.54	6.72	
Residing with care recipient	- .14	1.11	- .01
Symptomatic behaviours	.10	.08	.12
Relationship difficulties	- .12	.12	- .10
Family support	.22	.11	.16
Sense of mastery in caregiving	.29	.20	.14
Satisfaction in caregiving	.16	.07	.20
Subjective burden	- .31	.11	- .25*

Note. Adj. $R^2 = .00$ for model 1. Adj. $R^2 = .01$ for model 2. Adj. $R^2 = .12$ for model 3. Adj. $R^2 = .20$ for model 4. Adj. $R^2 = .24$ for model 5. Bonferroni corrections were performed to keep overall alpha level for the three regression equations at .05; * $p < .017$.

Table 11

Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Depressive Symptoms in Caregivers**(N = 128)**

Variables	B	SE B	Beta
model 1			
(constant)	12.57	1.28	
Residing with care recipient	1.80	1.69	.10
model 2			
(constant)	5.76	1.96	
Residing with care recipient	1.87	1.58	.10
Symptomatic behaviours	.44	.10	.36*
model 3			
(constant)	1.58	4.79	
Residing with care recipient	2.10	1.59	.11
Symptomatic behaviours	.36	.11	.30*
Relationship difficulties	.22	.14	.14
Family support	-.04	.16	-.02
model 4			
(constant)	20.47	8.07	
Residing with care recipient	1.61	1.51	.08
Symptomatic behaviours	.33	.11	.28*
Relationship difficulties	.04	.16	.03
Family support	.07	.16	.04
Sense of mastery in caregiving	- 1.01	.26	-.37*
Satisfaction in caregiving	.11	.10	.10

Table 11 (continued)

Variables	B	SE B	Beta
model 5			
(constant)	3.50	8.61	
Residing with care recipient	1.90	1.42	.10
Symptomatic behaviours	.24	.10	.20
Relationship difficulties	.01	.15	.00
Family support	.02	.15	.01
Sense of mastery in caregiving	-.67	.25	-.25*
Satisfaction in caregiving	.16	.09	.15
Subjective burden	.61	.15	.36*

Note. Adj. R^2 = .00 for model 1. Adj. R^2 = .13 for model 2. Adj. R^2 = .13 for model 3. Adj. R^2 = .22 for model 4. Adj. R^2 = .31 for model 5. Bonferroni corrections were performed to keep overall alpha level for the three regression equations at .05; * p < .017.

Table 12

Means and Standard Deviations of Variables included in the Moderation Analyses for Both Groups of Caregivers

Variables	Means and (Standard Deviations)	
	Coreidence Group (n = 74)	Separate Living Arrangement Group (n = 54)
Symptomatic behaviors of the care recipient	15.39 (7.25)	15.55 (8.60)
Relationship difficulties between caregiver and care recipient	26.19 (5.76)	27.39 (6.48)
Family support	13.39 (5.23)	14.01 (4.92)
Sense of mastery in caregiving	17.61 (3.07)	17.82 (3.99)
Satisfaction received from caregiving activities	26.21 (8.57)	25.09 (9.23)
Subjective Burden	20.57 (5.27)	21.17 (6.12)

Table 13

Summary of Standard Multiple Regression Analyses for Variables Predicting Subjective Burden in Both Groups of Caregivers.

Variables	B	SE B	Beta	B	SE B	Beta
	Coresidence Group (n = 74)			Separate Living Arrangement Group (n = 54)		
(Constant)	20.63	5.92		38.93	7.90	
Symptomatic behaviours	.20	.09	.27*	.11	.10	.16
Relationship difficulties	.10	.12	.11	-.089	.17	-.08
Family support	.13	.11	.13	.03	.16	.02
Sense of mastery	-.34	.21	-.20	-.85	.23	-.55*
Satisfaction in caregiving	-.06	.08	-.09	-.10	.08	-.16

Note. Bonferroni corrections were performed to keep overall alpha level for the two regression equations at .05; * $p < .025$.

For Coresidence Group, $F(5, 68) = 3.60, p < .01$; Adj. $R^2 = .15$; Sum of Squares Residual: 1603.38.

For Separate Living Arrangement Group, $F(5, 48) = 6.89, p < .001$; Adj. $R^2 = .36$; Sum of Squares Residual: 1156.99.

Table 14

Standard Multiple Regression Analyses of Subjective Burden on Relationship Between the Caregiver and the Person With Mental Illness and Sense of Mastery (N = 128)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	11.76	2.10		26.86	4.16	
Relationship difficulties	.34	.08	.37*	.17	.08	.19
Sense of mastery				-.60	.15	-.37*

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving relationship difficulties and sense of mastery at .05; * $p < .01$.

For Model 1, $F(1, 126) = 19.60, p < .001$; Adj. $R^2 = .13$.

For Model 2, $F(2, 125) = 19.56, p < .001$; Adj. $R^2 = .23$.

Table 15

Standard Multiple Regression Analyses of Subjective Burden on Satisfaction Received From Caregiving Activities and Sense of Mastery (N = 128)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	26.25	1.46		35.06	2.32	
Satisfaction in Caregiving	-.21	.05	-.33*	-.12	.05	-.18
Sense of mastery				-.64	.14	-.39*

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving satisfaction received from caregiving activities and sense of mastery at .05; * $p < .01$.
 For Model 1, $F(1, 126) = 15.47, p < .001$; Adj. $R^2 = .10$.
 For Model 2, $F(2, 125) = 19.86, p < .001$; Adj. $R^2 = .23$.

Table 16

Standard Multiple Regression Analyses of Subjective Burden on Relationship Between the Caregiver and the Person with Mental Illness and Sense of Mastery for Caregivers Residing with the Person with Mental Illness ($N = 74$)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	13.51	2.76		22.35	5.15	
Relationship difficulties	.27	.10	.30*	.20	.11	.22
Sense of mastery				-.40	.20	-.23

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving relationship difficulties and sense of mastery for caregivers residing with the person with mental illness at .05; * $p < .017$.

For Model 1, $F(1, 72) = 6.86, p < .01$; Adj. $R^2 = .07$.

For Model 2, $F(2, 71) = 5.60, p < .01$; Adj. $R^2 = .11$.

Conditions for mediation were not met.

Table 17

Standard Multiple Regression Analyses of Subjective Burden on Family Support and Sense of Mastery for Caregivers

Residing with the Person with Mental Illness (N = 74)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	20.47	1.71		37.84	3.19	
Family support	.01	.12	.01	.06	.12	.06
Sense of mastery				-.54	.20	-.31*

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving family support and sense of mastery for caregivers residing with the person with mental illness at .05; * $p < .017$.

For Model 1, $F(1, 72) = .00, p > .05$; Adj. $R^2 = .00$.

For Model 2, $F(2, 71) = 3.77, p < .05$; Adj. $R^2 = .07$.

Conditions for mediation were not met.

Table 18

Standard Multiple Regression Analyses of Subjective Burden on Satisfaction Received from Caregiving Activities and Sense of Mastery for Caregivers Residing with the Person with Mental Illness (N = 74)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	25.13	1.92		30.47	3.44	
Satisfaction in caregiving	-.17	.07	-.28*	-.12	.08	-.19
Sense of mastery				-.39	.21	-.23

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving satisfaction received from caregiving activities and sense of mastery for caregivers residing with the person with mental illness at .05; * $p < .017$.
 For Model 1, $F(1, 72) = 6.25, p < .05$; Adj. $R^2 = .07$.
 For Model 2, $F(2, 71) = 4.95, p < .01$; Adj. $R^2 = .10$.
 Conditions for mediation were not met.

Table 19

Standard Multiple Regression Analyses of Subjective Burden on Relationship Between the Caregiver and the Person with Mental Illness and Sense of Mastery for Caregivers Maintaining Separate Living Arrangement with the Person with Mental Illness (N = 54)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	9.85	3.32		35.71	7.32	
Relationship difficulties	.41	.12	.44*	.05	.14	.05
Sense of mastery				-.89	.23	-.58*

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving relationship difficulties and sense of mastery for caregivers maintaining separate living arrangement with the person with mental illness at .05; * $p < .017$.

For Model 1, $F(1, 52) = 12.28, p < .001$; Adj. $R^2 = .18$.

For Model 2, $F(2, 51) = 15.23, p < .001$; Adj. $R^2 = .35$.

Conditions for mediation were met. Unstandardized regression coefficients were significantly different ($t = 3.32, p < .01$), indicating a mediation effect.

Table 20

Standard Multiple Regression Analyses of Subjective Burden on Family Support and Sense of Mastery for Caregivers Maintaining Separate Living Arrangement with the Person with Mental Illness (N = 54)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	25.61	2.48		37.84	3.19	
Family support	-.32	.17	-.25	.00	.15	.00
Sense of mastery				-.94	.19	-.61*

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving family support and sense of mastery for caregivers maintaining separate living arrangement with the person with mental illness at .05; * $p < .017$.
 For Model 1, $F(1, 52) = 3.59, p > .05$; Adj. $R^2 = .05$.
 For Model 2, $F(2, 51) = 15.15, p < .001$; Adj. $R^2 = .35$.
 Conditions for mediation were not met.

Table 21

Standard Multiple Regression Analyses of Subjective Burden on Satisfaction Received from Caregiving Activities and Sense of Mastery for Caregivers Maintaining Separate Living Arrangement with the Person with Mental Illness (N = 54)

Variables	B	SE B	Beta	B	SE B	Beta
	Model 1			Model 2		
Constant	27.49	2.27		39.13	3.13	
Satisfaction in caregiving	-.25	.09	-.38*	-.12	.08	-.19
Sense of mastery				-.83	.18	-.54*

Note. Bonferroni corrections were performed to keep overall alpha level for the three regression equations for the mediation model involving satisfaction received from caregiving activities and sense of mastery for caregivers maintaining separate living arrangement with the person with mental illness at .05; * $p < .017$.

For Model 1, $F(1, 52) = 8.76, p < .01$; Adj. $R^2 = .13$.

For Model 2, $F(2, 51) = 17.21, p < .001$; Adj. $R^2 = .38$.

Conditions for mediation were met. Unstandardized regression coefficients were significantly different ($t = -2.36, p < .05$), indicating a mediation effect.

Appendix A
Social Behavioural Assessment Scale
(Platt, Weyman, Hirsch & Hewett, 1980)
modified version

1. In the last month, has your ill relative been miserable or in low spirits?
0 _____ no or little misery
1 _____ crying or obviously miserable for part of the time
2 _____ rarely cheerful; does not respond to attempts to cheer him/ her up

2. In the last month, has your ill relative kept to him/ herself?
0 _____ normally sociable
1 _____ socially withdrawn and solitary, but mixes with others when encouraged
2 _____ never sociable despite encouragements

3. In the last month, has your ill relative been slow in his or her movements and activities?
0 _____ no
1 _____ takes exceptionally long time to accomplish tasks
2 _____ so slow that he/ she could be a danger to self or others (e.g., crosses the street very slowly, doesn't react when a cigarette falls)

4. In the last month, has your ill relative had difficulty in remembering everyday things?
0 _____ no or infrequently
1 _____ definable lapses of memory
2 _____ so forgetful that he/ she cannot be trusted to do anything alone (e.g., cooking, shopping, travelling)

5. In the last month, has your ill relative done very little (e.g., sitting still in one place or lying on his/ her bed for long periods of time?)
0 _____ never or rarely
1 _____ definable underactivity but responds to encouragement to do things
2 _____ spends most of the time doing nothing and does not respond to encouragement to do things

6. In the last month, has your ill relative clung to you or to someone else or followed you around?
0 _____ never or rarely
1 _____ follows others around for some of the time
2 _____ will not remain on own even for few minutes

7. In the last month, has your ill relative found it difficult to make up his mind (e.g., difficulty deciding about things such as whether to go out or to stay home?, deciding about what to do?)
- 0 _____ never
 1 _____ quite often
 2 _____ so indecisive and unable to make up his mind that activities were disrupted
8. In the last month, has your ill relative found every events worrying or anxiety provoking?
- 0 _____ never or rarely
 1 _____ some worries but not totally preoccupied by them
 2 _____ constantly concerned with worries
9. In the last month, has your ill relative had any unusual fears?
- 0 _____ never or rarely
 1 _____ some unusual fears (e.g., elevators, going places) but no serious disruptions of activities
 2 _____ fears so important that situations which provoke them are totally avoided (e.g., avoiding going to certain places)
10. In the last month, has your ill relative been very finicky or fussy about doing things in a particular way (e.g., having a strict routine?, checking repeatedly that certain things are done?)
- 0 _____ never or rarely
 1 _____ some obsessional behaviours but no serious impairment of activities
 2 _____ extreme obsessional behaviours that seriously impair other activities
11. In the last month, has your ill relative expressed any strange or unusual ideas (e.g., saying that people are against him? saying that people are talking about him? hearing voices? or seeing things that are not really there?)
- 0 _____ never
 1 _____ some odd or strange ideas but not totally preoccupying
 2 _____ extremely odd or strange ideas, only minimal contact with reality
12. In the last month, has your ill relative been usually cheerful, excited or agitated (e.g., talking incessantly? being restless? being unable to sit through a meal or to stay in bed all night?)
- 0 _____ never
 1 _____ overactive but responds to efforts to control his/ her behaviour
 2 _____ uncontrollable, or overactive mostly at inconvenient time (e.g., night time)
13. In the last month, has your ill relative said or done anything that was completely out of character?
- 0 _____ never or rarely
 1 _____ some unpredictability but not leading to doubts about fitness for responsibilities
 2 _____ extreme unpredictability likely to have serious consequences for self or others

14. In the last month, has your ill relative been irritable?

- 0 _____ never or rarely
- 1 _____ often irritable but responds to attempts by others to change his/ her mood
- 2 _____ always snappy and bad tempered with family (even if polite to outsiders)

15. In the last month, has your ill relative been rude or inconsiderate to you or to your friends or relatives?

- 0 _____ never
- 1 _____ bad-mannered and inconsiderate but responds to attempts to change behaviour
- 2 _____ extremely rude, no response to attempt to change behaviour

16. In the last month, has your ill relative been threatening or abusive towards you or anyone else?

- 0 _____ never
- 1 _____ threatening in manner and/or verbally abusive but did not strike anybody or cause damage to property
- 2 _____ hit person or destroyed property (e.g., broke chair, window) on at least one occasion

17. In the last month, has your ill relative talked about taking his life or referred to his death, or has he/she deliberately harm him/ herself?

- 0 _____ never
- 1 _____ threatening to deliberately harm self, but not attempting to
- 2 _____ deliberately harming self

18. In the last month, other than the things you have already reported, has your ill relative done anything that was odd or unusual (e.g., making open sexual advances to friends or relatives, walking around the street muttering to him/ herself, dressing in bizarre fashion)?

- 0 _____ never
- 1 _____ some occasional odd behaviour
- 2 _____ most of his/ her behaviour is idiosyncratic or bizarre

19. In the last month, has your ill relative drunk heavily or abused drug (e.g., has his/ her drinking made it difficult for him/her to concentrate?, made life difficult for him/her in other ways?)

- 0 _____ never
- 1 _____ some, leading to disruption of activities
- 2 _____ extreme, leading to social problems (e.g., involvement of police services), or damage to health

20. In the last month, has your ill relative failed to look after him/ herself (has he kept him/ herself clean and tidy?, has he/ she eaten properly?)

0 _____ never

1 _____ needs guidance and supervision to prevent self-neglect

2 _____ neglects self despite efforts and suggestions of others

21. In the last month, has your ill relative looked for sympathy about aches and pains (has he/ she complained about tiredness or other bodily aches?)

0 _____ never or rarely

1 _____ complains about bodily ills frequently but not every day

2 _____ complains about bodily ills on most days

22. In the last month, has your ill relative said that he/ she did not want to take his/her medications anymore?, or that he/she did not need them anymore?

0 _____ never

1 _____ on occasion, he/ she suggests or tries to not take his/ her medications

2 _____ refuses his/ her medications even if reminded

23. In the last month, has your ill relative's sleeping habits been disturbed (e.g., difficulty falling asleep?, staying up very late?, getting up during the night?)

0 _____ sleeping habits not disturbed

1 _____ often stays up or walks around very late in the night or has difficulty falling asleep

2 _____ prevents others from sleeping at night, does not respond to advice to go to sleep

Appendix B
Burden Assessment Scale
 (Reinhard, Gubman, Horwitz & Minsky, 1994)

Here is a list of things that other people find to happen to them because of their relative's illness. Please, indicate to what extent you have had any of the following experiences in the past six months.

Because of your relative's illness, are you having:

1. Financial problems

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

2. Missing days at work (or school)

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

3. Finding it difficult to concentrate on your own activities

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

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

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

5. Cutting down on leisure time

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

6. Finding that the household routine is disrupted

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

7. Having less time to spend with friends

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

8. Neglecting other family members' needs

Not at all	A little	Some	A lot	NA
------------	----------	------	-------	----

9. Experiencing family frictions and arguments

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

10. Experiencing frictions with neighbours, friends or relatives outside the home

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

11. Becoming embarrassed because of your ill relative's behaviour

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

12. Feeling guilty because you are not doing enough to help

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

13. Feeling guilty because you feel responsible for causing your ill relative's problem

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

14. Resenting your ill relative because he/ she is making too many demands on you

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

15. Feeling trapped by your caregiving role

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

16. Being upset about how much your ill relative is changing from his or her former self

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

17. Worrying about how your behaviour with your ill relative might be making the illness worse

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

18. Worrying about what the future holds for your ill relative

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

19. Finding stigma of the illness upsetting

_____	_____	_____	_____	_____
Not at all	A little	Some	A lot	NA

Appendix C
Family Assessment Device - General Functioning subscale
(Epstein, Baldwin & Bishop, 1983)

Please, answer the following questions with regard to your relationship with your ill relative, and not your relationship with other family members.

1. Planning activities with my ill relative is difficult because we misunderstand each other.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

2. In times of crisis my ill relative and I can turn to each other for support.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

3. My ill relative and I cannot talk to each other about the sadness we feel.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

4. My ill relative and I accept each other for what we are.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

5. My ill relative and I avoid discussing our fears.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

6. My ill relative and I can express feelings to each other.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

7. There are lots of bad feelings between my ill relative and I.

<u>Strongly Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
---------------------------	--------------	-----------------	------------------------------

8. My ill relative and I feel accepted for what we are.

Strongly
Agree

Agree

Disagree

Strongly
Disagree

9. Making decisions is a problem for my ill relative and I.

Strongly
Agree

Agree

Disagree

Strongly
Disagree

10. My ill relative and I are able to make decisions about how to solve problems.

Strongly
Agree

Agree

Disagree

Strongly
Disagree

11. My ill relative and I don't get along well with each other.

Strongly
Agree

Agree

Disagree

Strongly
Disagree

12. My ill relative and I confide in each other.

Strongly
Agree

Agree

Disagree

Strongly
Disagree

Appendix D
Perceived Social Support from Family scale
(Procidano & Heller, 1983)

The following statements refer to feelings and experiences that occur to most people at one time or another in their relationships with their families. Please, answer each statement in terms of the support you receive from family members other than your ill relative.

1. My family gives me the moral support I need
Yes _____ No _____ Don't know _____
2. I get good ideas about how to do things or make things from my family
Yes _____ No _____ Don't know _____
3. Most other people are closer to their family than I am
Yes _____ No _____ Don't know _____
4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable
Yes _____ No _____ Don't know _____
5. My family enjoys hearing about what I think
Yes _____ No _____ Don't know _____
6. Members of my family share many of my interests
Yes _____ No _____ Don't know _____
7. Certain members of my family come to me when they have problems or need advice
Yes _____ No _____ Don't know _____
8. I rely on my family for emotional support
Yes _____ No _____ Don't know _____
9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later
Yes _____ No _____ Don't know _____
10. My family and I are very open about what we think about things
Yes _____ No _____ Don't know _____
11. My family is sensitive to my personal needs
Yes _____ No _____ Don't know _____

12. Members of my family come to me for emotional support
Yes _____ No _____ Don't know _____
13. Members of my family are good at helping me solve problems
Yes _____ No _____ Don't know _____
14. I have a deep sharing relationship with a number of members of my family
Yes _____ No _____ Don't know _____
15. Members of my family get good ideas about how to do things or make things from me
Yes _____ No _____ Don't know _____
16. When I confide in members of my family, it makes me uncomfortable
Yes _____ No _____ Don't know _____
17. Members of my family seek me out for companionship
Yes _____ No _____ Don't know _____
18. I think that my family feels that I'm good at helping them solve problems
Yes _____ No _____ Don't know _____
19. My relationships with family members are not as close as other people's relationships with their family
Yes _____ No _____ Don't know _____
20. I wish my family was different
Yes _____ No _____ Don't know _____

Appendix E
Care Work Satisfaction Scale
(Orbell, Hopkins & Gillies, 1993)

Please, indicate the extent to which you agree with the following statements about your experiences in caregiving.

1. Caring for my ill relative makes me feel good about myself.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Moderately	Neither agree	Moderately	Disagree	
Strongly	Agree	Agree	nor disagree	disagree		disagree

2. The responsibility of caring for my ill relative gives me an important sense of satisfaction.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Moderately	Neither agree	Moderately	Disagree	
Strongly	Agree	Agree	nor disagree	disagree		disagree

3. Caring for my ill relative makes me feel valued.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Moderately	Neither agree	Moderately	Disagree	
Strongly	Agree	Agree	nor disagree	disagree		disagree

4. Caring for my ill relative is a real source of pleasure to me.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Moderately	Neither agree	Moderately	Disagree	
Strongly	Agree	Agree	nor disagree	disagree		disagree

5. I find my caring activities fulfilling and rewarding.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Moderately	Neither agree	Moderately	Disagree	
Strongly	Agree	Agree	nor disagree	disagree		disagree

6. Caring for my ill relative makes me happy.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Moderately	Neither agree	Moderately	Disagree	
Strongly	Agree	Agree	nor disagree	disagree		disagree

Appendix F
Mastery scale
(Pearlin & Schooler, 1978)

Please, indicate the extent to which you agree with the following statements about your experiences in caregiving.

1. I have little control over the things that happen to me in the context of caregiving.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
--------------------------	--------------	-----------------	-----------------------------

2. There is really no way I can solve some of the problems which arise out of caring for my ill relative.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
--------------------------	--------------	-----------------	-----------------------------

3. There is little I can do to change the caregiving situation I am involved in.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
--------------------------	--------------	-----------------	-----------------------------

4. I often feel helpless in dealing with my ill relative.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
--------------------------	--------------	-----------------	-----------------------------

5. Sometimes I feel that I'm being pushed around in life.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
--------------------------	--------------	-----------------	-----------------------------

6. What happens to me and to my caregiving situation in the future mostly depends on me.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
--------------------------	--------------	-----------------	-----------------------------

7. I can do just about anything I really set my mind to do when caring for my ill relative.

<u>Strongly</u> Agree	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> Disagree
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Appendix G
Centre for Epidemiologic Studies Depression Scale
(Radloff, 1977)

Below is a list of the ways in which you may sometimes feel or behave. Please indicate how often you have felt this way during the past week.

1. I am bothered by things that usually don't bother me.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time
2. I do not feel like eating; my appetite is poor.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time
3. I feel that I cannot shake off the blues even with help from my family or friends.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time
4. I feel that I am just as good as other people.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time
5. I have trouble keeping my mind on what I am doing.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time
6. I feel depressed.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time
7. I feel that everything I do is an effort.
 (Less than 1 day)_____ (1 to 2 days)_____ (3 to 4 days)_____ (5 to 7 days)_____
 Rarely or none some or little occasionally or most or all
 of the time of the time moderate of the time

8. I feel hopeful about the future.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

9. I think my life is a failure.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

10. I am fearful.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

11. My sleep is restless.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

12. I am happy.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

13. I talk less than usual.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

14. I feel lonely.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

15. People are unfriendly.

(Less than 1 day)_____	(1 to 2 days)_____	(3 to 4 days)_____	(5 to 7 days)_____
Rarely or none of the time	some or little of the time	occasionally or moderate	most or all of the time

- | | | | |
|---|---|---|--|
| <p>16. I enjoy life.
 (Less than 1 day)____
 Rarely or none
 of the time</p> | <p>(1 to 2 days)____
 some or little
 of the time</p> | <p>(3 to 4 days)____
 occasionally or
 moderate</p> | <p>(5 to 7 days)____
 most or all
 of the time</p> |
| <p>17. I have crying spells.
 (Less than 1 day)____
 Rarely or none
 of the time</p> | <p>(1 to 2 days)____
 some or little
 of the time</p> | <p>(3 to 4 days)____
 occasionally or
 moderate</p> | <p>(5 to 7 days)____
 most or all
 of the time</p> |
| <p>18. I feel sad.
 (Less than 1 day)____
 Rarely or none
 of the time</p> | <p>(1 to 2 days)____
 some or little
 of the time</p> | <p>(3 to 4 days)____
 occasionally or
 moderate</p> | <p>(5 to 7 days)____
 most or all
 of the time</p> |
| <p>19. I feel that people dislike me.
 (Less than 1 day)____
 Rarely or none
 of the time</p> | <p>(1 to 2 days)____
 some or little
 of the time</p> | <p>(3 to 4 days)____
 occasionally or
 moderate</p> | <p>(5 to 7 days)____
 most or all
 of the time</p> |
| <p>20. I cannot get "going".
 (Less than 1 day)____
 Rarely or none
 of the time</p> | <p>(1 to 2 days)____
 some or little
 of the time</p> | <p>(3 to 4 days)____
 occasionally or
 moderate</p> | <p>(5 to 7 days)____
 most or all
 of the time</p> |

Appendix H
Satisfaction With Life Scale
 (Diener, Emmons, Larsen & Griffin, 1983)

Please, indicate the extent to which you agree with the following statements.

1. In most ways my life is close to my ideal.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Slightly	Neither agree	Slightly	Disagree	
Strongly		Agree	nor disagree	disagree		disagree
Agree						

2. The conditions of my life are excellent.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Slightly	Neither agree	Slightly	Disagree	
Strongly		Agree	nor disagree	disagree		disagree
Agree						

3. I am satisfied with my life.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Slightly	Neither agree	Slightly	Disagree	
Strongly		Agree	nor disagree	disagree		disagree
Agree						

4. So far I have obtained the important things I want in my life.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Slightly	Neither agree	Slightly	Disagree	
Strongly		Agree	nor disagree	disagree		disagree
Agree						

5. If I could live my life over, I would change almost nothing.

1 _____	2 _____	3 _____	4 _____	5 _____	6 _____	7 _____
Strongly	Agree	Slightly	Neither agree	Slightly	Disagree	
Strongly		Agree	nor disagree	disagree		disagree
Agree						

**Appendix I
Communication Script with Mental Health Professionals**

My name is Anne-Marie Baronet. I am a doctoral student in Psychology at the University of Ottawa working under the supervision of Dr. Gary Gerber. I am conducting a study with family members and close friends caring for a person with severe mental illness. The purpose of the study is to understand how certain factors predict the feelings of subjective burden often experienced by people caring for a family member or a close friend with severe mental illness. I am contacting you in the hope that you can help me recruit participant caregivers by allowing me to present the study in the support group you are leading.

Participation in the study consists of answering a one hour long questionnaire which evaluates the extent of symptoms and disruptive behaviors in the person with mental illness, the resulting disruptions in the caregiver's life, the relationship between the caregiver and the person with mental illness, the support the caregiver receives from other family members, satisfaction from caregiving activities, feelings of mastery in caregiving, feelings of subjective burden, caregiver symptoms of depression as well as overall life satisfaction. Caregivers who complete the questionnaire will receive \$20. as a compensation for their time.

The information obtained will be treated in a confidential and anonymous manner. The filled questionnaires will be kept in a locked cabinet in my office, and only myself and the other researchers involved in the project will have access to them. The questionnaires will be identified by ID numbers and not by names. Demographic information and answers to questions will be summarized and reported for the whole group of participants. A summary of the study findings will also be made available to participants after the study is completed.

If you agree, I would like to present the study at the beginning of a group meeting. I could then leave some envelopes including questionnaires and consent forms with you, and caregivers could get one if they choose to participate in the study. The envelopes are pre-addressed, so caregivers can return them to me directly by mail.

Appendix J Recruitment Script

I would like to take a few minutes of your time today to talk to you about a research project I am conducting with family members and close friends caring for a person with severe mental illness. My name is Anne-Marie Baronet. I am a doctoral student in Psychology at the University of Ottawa working under the supervision of Dr. Gary Gerber. The purpose of the study is to understand how certain factors predict the feelings of subjective burden often experienced by people caring for a family member or a close friend with severe mental illness. Hopefully, the study will help clinicians understand caregivers and provide them with appropriate support.

If you choose to participate in the study, your participation will consist of answering a one hour long questionnaire in which you will provide information about yourself (i.e., demographic characteristics) and your experience of caring for a person with severe mental illness. The questionnaire also include questions about the extent of symptoms and disruptive behaviors in the person you are caring for, as well as the resulting disruptions in your life. It includes questions about your relationship with that person, the support you are receiving from other family members, the satisfaction you receive from caregiving activities, your feelings of mastery in caregiving activities, your feelings of subjective burden, symptoms of depression you might be feeling as well as your overall level of life satisfaction. As the questionnaire deals with personal and sensitive information, it could elicit emotional reactions such as sadness or worry in thinking about the person you are caring for.

Each of these envelopes include a questionnaire, two consent forms and a separate form on which you can write your address. The envelopes are pre-addressed and pre-stamped, so that you can return easily one questionnaire, one signed consent form and the form that includes your address. The other consent form is for you to keep. Upon reception of the completed questionnaire, I will send you by mail a \$20. check, as a compensation for your time. If you do not feel at ease about receiving money, a donation in your name to an association of your choice can also be arranged. I will leave the envelopes with your group leader, so that you can take one at the end of your group if you are interested to participate.

To participate in the study, you must be caring for a relative or a friend with a severe mental illness such as schizophrenia or bipolar disorder. Unfortunately, people caring for someone with a physical illness or a cognitive impairment such as dementia cannot be included in the study. You must be the person most involved in caring for the family member or friend with the severe mental illness. It is not necessary to be residing with the person you are caring for to participate in the study.

Your participation in this study is strictly voluntary, and you will be able to withdraw at any time. The information you share with me will be treated in a confidential manner. The filled questionnaires will be kept in a locked cabinet in my office, and only myself and the other researchers involved in the project will have access to them. Your answers will not be made

available to any other individuals. Your answers to questionnaires will also be treated in an anonymous manner. The questionnaires will be identified by an ID number and not by your name. Demographic information will be summarized and reported for the whole group of participants in the form of averages (e.g., age, number of years of education) and percentages (e.g., gender, kinship with the person you are caring for). Your answers will be computed and interpreted for the whole group of participants. You will not be quoted, and only pooled answers will be reported, not individual scores. In no way will your name be associated with your answers.

A summary of the study findings will also be sent to participants who will indicate an interest in obtaining them.

**Appendix K
Consent Form**

I, _____, am interested in participating in this study on the experience of caring for a family member with mental illness conducted by Anne-Marie Baronet, doctoral student and supervised by Dr. Gary Gerber, Clinical Assistant Professor at the School of Psychology of the University of Ottawa. The purpose of this study is to better understand the experience of caring for a person with mental illness, and how certain factors may alleviate feelings of burden often felt by caregivers.

Provided that I agree to participate, my participation will consist of answering a one hour long questionnaire in which I will provide information about myself (demographic characteristics) and my experience of caring for a person with mental illness. The questionnaire will evaluate the extent of symptomatic behaviors in the person with mental illness and the resulting effects on my life, characteristics of my relationship with my relative or friend who has a mental illness, support I get from other family members, satisfaction I receive from caregiving activities, how I feel emotionally and satisfaction with my life. I will receive \$20 upon completion of the questionnaire. I understand that the doctoral student's duties is to collect information, and that she will not be in a position to offer advices or help. I also understand that because this activity deals with very personal information, it may include emotional reactions which may, at times, be negative (e.g., sadness or worry in thinking about myself and my relative or friend who has a mental illness).

My participation is strictly voluntary and I am free to withdraw from the study at any time or refuse to participate without any penalty. If I am uncomfortable with any particular question, I may refuse to answer. The information I will share will remain strictly confidential. The filled questionnaires will be kept in a locked cabinet in the doctoral student's office, and only the researchers involved in the project will have access to them. My answers will not be made available to any other individuals. My answers to the questionnaire will also be treated in an anonymous manner. The questionnaire will be identified by an ID number and not by my name. Answers will be computed and interpreted for the whole group or subgroups of participants (e.g., men vs. women). Participants will not be quoted, and only pooled answers will be reported, not individual scores. Demographic information will be summarized and reported for the whole group of participants in the form of averages (e.g., age, number of years I resided with my ill relative) and percentages (e.g., gender, kinship with my ill relative). In no way will my name be associated with my answers.

I know that I can receive a copy of the study findings if I wish to (please, place a mark here if you wish to ____). There are two copies of this consent form, one for the researcher to keep and one for me to keep. If I have any questions or concerns, I may call Ms. Baronet at (780) 420-0975. I may also call Dr. Gerber at (613) 345-3476 ext.2396.

Participant's signature: _____

Date: _____

Researcher's signature: _____

Date: _____