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BURDEN ASSESSMENT SCALE FOR FAMILIES OF THE SERIOUSLY MENTALLY ILL

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ABSTRACT

Although there are many scales of family burden that are available and in use, there is no accepted standard. This paper describes a scale developed to assess the burden of families with a seriously mentally ill member. The Burden Assessment Scale (BAS), consisting of 19 items, is shown to have excellent reliability. Use of the BAS in two separate studies reveals the scale to have a stable factor structure, whether it is self- or interviewer-administered. The scale differentiates between family samples with different levels of burden and is sensitive to changes over time. The BAS, which is brief, reliable, and valid, is a practical tool for use in program evaluation.

INTRODUCTION

The dramatic deinstitutionalization of mentally ill patients over the past 35 years has greatly increased the burdens on their families. Between 1955 and 1988, the number of patients residing in public psychiatric hospitals fell by 82% (Mechanic & Rochefort, 1992) with a corresponding decline in available beds (NIMH, 1990). Somewhere between one-third and two-thirds of patients who are admitted to these institutions return to live with

family members upon discharge (Goldman, 1982). Family care of the mentally ill is particularly difficult because families must not only provide basic caregiving services but also handle disruptive symptoms.

More than three decades of research demonstrate that families of the seriously mentally ill are burdened by their responsibilities (Clausen & Yarrow, 1955; Fisher, Benson, & Tessler, 1990; Grad & Sainsbury, 1968; Kreisman & Joy, 1974; Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991). A recent National Institute of Mental

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Health (NIMH) report indicates that the ramifications of family caregiving are a major priority (1991:12–13). NIMH's (1991) *National Plan of Research to Improve Services* underscores the need to understand family burden to enhance individual responses and develop supportive services for family caregivers.

There is broad consensus that burden is multifaceted. British researchers Hoenig and Hamilton (1966) were the first to conceptualize burden explicitly in terms of two broad dimensions, objective and subjective burden. Subsequent research has concurred in distinguishing concrete problems, or objective burdens, from subjective feelings of distress (Hatfield, 1978; Platt, 1985). There is also substantial agreement regarding specific kinds of objective and subjective burdens, such as financial strain and feelings of stigma (Platt, 1985).

The importance of the concept of burden has grown as research and organized models of family involvement have led to a rich variety of programs intended not only to reduce decompensation among the seriously mentally ill, but also to alleviate family burden (Falloon & Pederson, 1985; Hatfield, 1990; Landeen et al., 1992; Pfeiffer & Mostek, 1991; Stein & Test, 1976). Crucial to assessing the effectiveness of these programs is a standard scale that is reliable, conceptually meaningful, and convenient to use.

Although a number of burden measures exist, several factors limit their usefulness. Two of the best known family burden scales are difficult to administer because they require interviewer ratings of family members' burden (Creer, Sturt, & Wykes, 1982; Platt, Weyman & Hirsch, 1983). Some measures combine specific facets of burden with global well-being represented by the caregiver's overall physical and mental health (Hatfield, 1978; Hoenig & Hamilton, 1966; Pai & Kapur, 1981; Platt et al., 1983). Other measures contain items that combine caregiver consequences and the ill family member's behaviors or the family's coping skills and expectations of the ill relative (Cook & Pickett, 1987; Grad & Sainsbury, 1963, 1968; Hoenig & Hamilton, 1966; Spitzer, Gibbon, & Endicott, 1971; Tessler, Fisher, & Gamache, 1992). Such measures may underrepresent the considerable burden of families who do not live with their ill relative (Carpentier, Lesage, Goulet, Lalonde, & Renaud, 1992).

There is a pressing need in the evaluation of programs for families of mentally ill relatives for a conceptually clear and easily administered family-burden instrument, that is not dependent on the living situation of the ill family member. A brief burden scale that focuses on specific objective and subjective caregiver consequences would also facilitate inclusion of family burden among program outcomes, since support programs for families can have multiple goals for ill family members as well as family participants.

THE BURDEN ASSESSMENT SCALE (BAS)

The Burden Assessment Scale (BAS) developed by Reinhard and Horwitz (see Appendix) contains 19 items that capture both objective and subjective consequences of providing ongoing care to the seriously mentally ill. The scale distinguishes burden from the measurement of the ill relative's disruptive behaviors and the family's caregiving activities. These are viewed as *predictors* rather than aspects of burden.

Ten items assess the extent to which primary caregivers experience objective burden because of their caregiving responsibilities. Objective burden items refer to the potentially observable behavioral effects of caregiving (Platt, 1985) in several areas including financial problems, limitations on personal activity, household disruption, and social interactions. Items measuring financial distress (1) and disruptions in household routines (6) are based on the work of Test and Stein (1980). Four items (2–5) operationalize limitations on personal activity: missed days at work or school (Grad & Sainsbury, 1963; Test & Stein, 1980); difficulty concentrating on activities (Platt et al., 1983); reduced leisure time (Platt et al., 1983); and changes in personal plans (Robinson, 1983; Test & Stein, 1980). Finally, four items (7–10) assess potential negative effects on social interactions including neglecting friends (Platt et al., 1983) or other family members (Freeman & Simmons, 1963) and frictions within the family (Platt et al., 1983) or with persons outside the home boundaries (Grad & Sainsbury, 1963).

Nine items measure several aspects of subjective burden, including the feelings, attitudes, and emotions expressed about the caregiving experiences (Platt, 1985). Areas of subjective burden include shame, stigma, guilt, resentment, grief, and worry. Two items based on the work of Zarit, Reever, and Bach-Peterson (1980) and Freeman and Simmons (1963) measure shame (11) and stigma (19). The Zarit et al. (1980) study also provides the basis for one item (12) that assesses guilt for not doing enough to help. A measure of guilt for causing the illness (13) is based on the family advocacy literature describing the anguish that families suffer from family-as-agents explanations of mental illness (Hatfield & Lefley, 1987). The two resentment items (14, 15, resenting excessive demands and feeling trapped) are based on the work of Thompson and Doll (1982). The grief item (16), which measures the extent to which respondents are upset about the change from their ill relatives' former selves, stems from the studies of Hatfield (1978) and Robinson (1983).

Finally, two items measure worry. The first measures worry about how the caregiver's behavior with the ill relative might make the illness worse (17). This item is based on Lefley's (1987) notion that the persistent requirement to self-monitor one's behavior to prevent the

relative's relapse is a significant part of subjective burden. The second item, regarding worry about the future (18), stems from the research of Herz, Endicott and Spitzer (1976) and Tessler, Killian, and Gubman (1987).

To evaluate the content validity of this set of potentially negative caregiving consequences, a caregiver advisory group of six family members of long-term mentally ill adults reviewed the burden instrument for clarity and completeness. Their feedback supported the content, and their suggestions for clarity were incorporated for pilot testing before the simultaneous use of the scale in the two studies reported here.

Two Studies Applying the BAS

Horwitz and Reinhard conducted a study that focused on the burden experiences of 94 family members of severely mentally ill adults participating in "The Club," a New Jersey community aftercare program (Horwitz & Reinhard, 1992; Reinhard, 1994). Based on the Fountain House model of psychiatric rehabilitation (Beard, 1978), the Club offers complete services from residential to partial care and vocational rehabilitation.

In this study, any primary caregiver of a Club member was eligible to participate. Club members first provided consent to contact the family member "most involved with helping you manage your situation." Hence, consenting family members were selected on the basis of their ill relatives' participation in the Club program, not their own use of mental health services. Using a cross-sectional design, data were collected through a 90-minute, in-home structured interview that included a broad range of measures as well as the BAS.

The 94 family members in the second study were participants in a new initiative by New Jersey's Division of Mental Health and Hospitals (DMH&H) intended to provide intensive support to family members with a seriously mentally ill relative. The purpose of the study was to monitor and evaluate program outcomes. A self-selected family respondent was asked to provide information at program intake and at two 3-month intervals. Data included the self-administered BAS as well as sociodemographic and clinical information about the family and its ill member. Program staff provided information concerning the family's service contacts. The 94 family members were those for whom both initial and 6-month data were available.

While the Club was a self-contained service within a single county, the DMH&H study included intensive family support services (IFSS) in eight counties. Each IFSS offered different service packages. All programs provided individual consultations to families; some also offered respite care to the family or its ill member, psychoeducation groups, family support groups, or advocacy and referral services (Gubman, Minsky, & Schorske, 1991). Although the BAS items were identical for both

studies, the method of administration differed. Information from the Club sample was obtained from interviewers, while in the DMH&H study this scale was self-administered.

Table 1 summarizes the sample characteristics of both studies. Parents, mainly mothers, predominated in both samples. The average age was slightly above 55 years. In addition, the majority of participants in both studies were caring for family members suffering from schizophrenia (57.4% and 77.7% for the DMH&H and Club studies, respectively), but were not members of a self-help advocacy organization, such as the National Alliance For the Mentally Ill (NAMI) or a state affiliate.

The composition of the DMH&H sample was somewhat more varied than the Club sample. Whereas 82% of the primary caregivers in the Club study were female and 96% were white, almost one-third of the DMH&H sample were men and 81% were white. The difference in sample-selection procedure most likely accounts for the gender difference, because patients typically selected their mother as their primary caregiver in the Club study, while any family member was free to participate in the DMH&H study.

TABLE 1
SAMPLE CHARACTERISTICS

Variables	DMH&H (N = 94)		Club (N = 94)	
	N	%	N	%
Relationship				
Parent	68	72.4	64	68.1
Sibling	7	7.4	14	14.9
Child	5	5.3	11	11.7
Other	14	14.9	5	5.3
Sex				
Male	29	30.8	17	18.1
Female	64	68.1	77	81.9
Missing	1	1.1	0	0.0
Age				
<35	8	8.5	9	9.6
35-54	30	31.9	25	26.6
55-74	42	44.7	54	57.4
>75	8	8.5	6	6.4
Missing	6	6.4	0	0.0
	M = 56.5		M = 58.0	
Race				
White	76	80.8	90	95.7
Black	14	14.9	2	2.1
Hispanic	3	3.2	2	2.1
Missing	1	1.1	0	0.0
Living with relative	65	69.1	34	36.2
Relative has schizophrenia	54	57.4	73	77.7
NAMI member	28	29.8	20	21.3

The Club sample clearly overrepresents whites compared to their proportions either in the county population or among county recipients of community mental health services, which were respectively 81.8% and 68.9% white (DMH&H, 1991). While the DMH&H sample includes several counties with greater minority representation, the family samples contained fewer minorities than one would expect. The underrepresentation of minorities is consistent with other similar studies, which suggests that family self-help groups experience difficulties in attracting and enrolling minority family members (Biegel & Milligan, 1992; Steinwachs, 1991).

Compared to the Club participants, about twice as many participants in the DMH&H study lived with their ill family relatives (69% compared to 36%). The Club offers a unique total service package, including assistance in locating housing. The DMH&H sample is more representative of the situation statewide for family members whose ill relatives are recipients of public mental health services (DMH&H, 1991).

Reliability, Factor Structure and Properties of the BAS

In both studies, burden scores were obtained by asking respondents to indicate on a 4-point Likert scale the extent to which they had experienced burden in each of the 19 areas covered. Responses were summed, with higher scores indicating greater levels of caregiver burden. The internal reliability of the scale, estimated by Cronbach's alpha (Cronbach, 1951), was similar in both studies (.91 and .89 for the DMH&H and Club studies, respectively).

To clarify and verify the conceptual structure of the BAS and determine the stability of the factor structure across populations, burden ratings for the 19 items were submitted to separate principal components factor analysis with varimax rotation. The sample size of each study essentially met the minimum requirements of five cases per item (Tabachnick & Fidell, 1989). Table 2 shows the results of the factor analysis using the data from the DMH&H study. A conventional eigen-value criterion of 1.0 (Nunnally, 1978) was used to determine the number of factors selected. The five-factor solution accounted for 66.4% of the variance in these data.

The expectation was that objective and subjective burden items would load on discrete factors, although the multidimensional nature of these two broad dimensions might not yield a two-factor solution. Consistent with this expectation, with the exception of friction with others, objective burden items did not load on the same factors as the subjective items. At the same time, the factor analysis of the DMH&H burden data, yielding five discrete factors, provides evidence that objective and subjective burdens are multidimensional.

Six items loaded on factor I, *Disrupted Activities*. These items (3–8) included distractions, changed plans and household routines, and reduced time for self,

TABLE 2
ROTATED (VARIMAX) FACTOR STRUCTURE
OF THE BAS, DMH&H

Item	Factor Loadings ^a				
	I	II	III	IV	V
1. Financial problems	.39	.33	-.01	-.12	.38
2. Missed work/school	.23	.09	.10	.16	.81
3. Difficulty concentrating	.60	.21	.43	.19	.13
4. Change personal plans	.85	.24	.08	.13	-.02
5. Reduced leisure time	.81	.18	.14	.13	.12
6. Upset household routine	.65	.23	.21	.15	.37
7. Less time for friends	.80	.14	.24	.11	.18
8. Neglected family's needs	.71	.22	.04	.24	.32
9. Family frictions	.24	.37	.29	.17	.52
10. Frictions with others	.24	.62	.10	.08	.34
11. Embarrassed	.33	.64	.09	.25	-.04
12. Guilty not helping enough	.16	.24	.08	.74	.26
13. Guilty for causing illness	.14	.09	.16	.86	.06
14. Resented demands	.08	.81	.12	.15	.10
15. Felt trapped	.29	.71	.19	.10	.11
16. Upset about relative's change	.22	.26	.64	.20	-.23
17. Worry make illness worse	.32	.21	.42	.54	-.08
18. Worry about future	.10	-.07	.76	.06	.26
19. Stigma upsetting	.13	.30	.63	.14	.18
Percent of explained variance	40.4	8.1	6.8	5.7	5.4
Total explained variance = 66.4%					

Note. Decimals are rounded.

^aBoldface indicates heavier loadings that define each factor.

friends, and other family members. This component explained 40.4% of the variance in burden and is similar to the factor of activity restrictions described in the gerontological literature (Kosberg, Cairl, & Keller, 1989; Novak & Guest, 1989; Poulshock & Deimling, 1984).

Four items (10, 11, 14, 15) loaded on factor II, which explained an additional 8.1% of the variance. This component of burden refers to the *Personal Distress* that arises from experiencing frictions with persons outside the household, being embarrassed by disruptive behaviors, and feeling trapped and resentful.

Factor III, *Time Perspective*, contained three items (16, 18, 19) that captured a negative temporal aspect of managing mental illness. Family caregivers were upset about past and lost possibilities for their relative, present stigma, and future plans. This component of burden accounted for an additional 6.8% of the explained variance in burden.

Factor IV, *Guilt*, encompassed three items (12, 13, 17) and explained 5.7% of the variance. Family members' guilt for not doing enough to help their ill relative clustered with guilt for causing the illness or precipitating exacerbations through interactions with their ill relative.

Factor V (items 2 and 9) refers to *Basic Social Functioning*, or significant alterations in the social spheres of work (missing days at work/school) and family (fric-

tions and arguments). This factor explained 5.4% of the variance.

For the most part, objective and subjective dimensions were distinct. Two factors, *Disrupted Activities* (I) and *Basic Social Functioning* (V), composed objective burden. Three factors—*Personal Distress* (II), *Time Perspective* (III), and *Guilt* (IV)—constituted subjective burden.

Table 3 shows the results of the factor analysis using the data from the Club study. The analysis also yields a five-factor solution that explains 66.3% of the variance in these data, and is substantially similar to that found in the DMH&H study. Factor I, also capturing a *Disrupted Activities* component of burden, explained 37.2% of the variance. Other than “missed days at work” and “feeling trapped,” which also loaded on other factors, items were similar to those found in the DMH&H study. Factor II here, explaining an additional 9.7% of the variance, also captured *Personal Distress*, although it included three additional items: financial distress (which loaded at a low level in the DMH&H analysis); stigma (which also loaded on the Time Perspective factor); and family frictions. Factor III represents the *Guilt* component for these data, explaining an additional

7.9% of the variance, while factor IV resembles the *Time Perspective* component, and explains an additional 6% of the variance.

Factor V in the Club analysis is markedly different from the results obtained in the DMH&H study. Explaining an additional 5.4% of the variance, it captured a *Worry* dimension of burden in which caregivers were so focused on their ill relative’s needs that they found it difficult to concentrate on their own activities, yet felt that what they are doing was not enough to meet those needs.

Analyses of the factor structure of the BAS in these two studies indicate that burden is a multidimensional phenomenon, that objective and subjective burden are distinguishable, and that the conceptual structure of the scale is fairly stable. It is interesting to note that in both studies, disruption of everyday activities was the major component of burden, followed by personal distress. However, the fact that the two samples did not yield identical factors mitigates against using them as subscales.

VALIDITY OF THE BAS

If the BAS is a valid measure of burden, the DMH&H sample should report higher levels of burden than the Club sample. The primary basis for this prediction is that the DMH&H sample consists of families who sought mental health services for themselves while the Club sample did not.

The data support this prediction, indicating mean burden scores of 55.3 for the DMH&H sample and 32.1 for the Club sample. Although the magnitude of burden varied as predicted, it is interesting to note that a ranking of the item means for both studies show that the nature of burden was strikingly similar. Families reported the greatest average burden from their worry about the future (3.6 and 3.4 for the DMH&H and Club samples, respectively) and unrelenting grief (3.1 and 2.2 for the DMH&H and Club samples). Families in both samples considered missing days at work, frictions with neighbors, and guilt for causing the illness as least burdensome.

UTILITY OF THE BAS

One goal of the DMH&H evaluation of its IFSS programs was to ascertain whether these services contributed to reduction of family burden. Reported here are data related to changes in burden over time and analyses that explain these changes.

As expected, there were changes in the BAS score over the six-month period. Mean burden scores went from 55.3 at baseline to 40.8 at the six-month follow-up, a result significant at the .001 level.

In addition, differential reduction in burden could be explained by service use. In the regression analysis re-

TABLE 3
ROTATED (VARIMAX) FACTOR STRUCTURE
OF THE BAS, CLUB STUDY

Item	Factor Loadings ^a				
	I	II	III	IV	V
1. Financial problems	.44	.61	.09	.03	-.03
2. Missed work/school	.54	-.14	.54	-.10	.12
3. Difficulty concentrating	.46	.26	.06	.04	.53
4. Change personal plans	.57	.23	.21	.17	-.07
5. Reduced leisure time	.87	.01	-.04	.12	.10
6. Upset household routine	.51	.46	.38	.22	.16
7. Less time for friends	.78	.35	.09	.12	.14
8. Neglected family’s needs	.57	.32	.53	.01	.08
9. Family frictions	.41	.52	.30	.02	.32
10. Frictions with others	.31	.61	.42	-.18	-.21
11. Embarrassed	.02	.65	-.08	.34	.23
12. Guilty not helping enough	-.02	-.02	.23	.04	.81
13. Guilty for causing illness	.02	.08	.80	.14	.18
14. Resented demands	.23	.62	.15	.10	.47
15. Felt trapped	.48	.46	.06	.23	.43
16. Upset about relative’s change	.05	.20	.15	.76	.18
17. Worry make illness worse	.09	.16	.52	.31	.40
18. Worry about future	.24	-.01	.06	.82	-.01
19. Stigma upsetting	.01	.59	.00	.55	-.04
Percent of explained variance	37.2	9.7	7.9	6.0	5.4
Total explained variance = 66.3%					

Note. Decimals are rounded.

^aBoldface indicates heavier loadings that define each factor; underlining indicates items that load onto three factors, or load equally onto two factors.

ported in Table 4, the burden-change score is the dependent variable. Explanatory service variables are the total number of concurrent services and the number of single family contacts (the only service common to all eight programs) over the six-month period. The analysis controls for the age and diagnosis of the ill family member. The analysis also controls for the role and number of family participants. Finally, to explore the possibility that program effects might reflect statistical regression toward the mean, the level of initial burden is included in the model.

As Table 4 indicates, the model accounts for 47% of the variance in change in reported burden after six months of program participation. The ill family member's age and diagnosis are not predictive, nor is the involvement of the ill family member's mother. All other explanatory variables are significant. The strongest effect is the impact of the initial level of reported burden. However, program characteristics make some contribution to reduced burden. The more types of services received and the more single family contacts, the greater the reported reduction in family burden. Interestingly, the total number of participants has a significant effect, although not in the anticipated direction. Families with more members involved in intensive family-support services are less likely to experience reductions in burden.

These findings are consistent with other research reporting benefits from multiple services, particularly those providing opportunities for families to interact (McFarlane & Dunne, 1991). In addition, the results suggest that adherence to a single treatment model may not be the optimal approach to reducing family burden. They also suggest further validation of the BAS by showing that program participation reduces burden levels over time.

CONCLUSION

These analyses provide preliminary evidence that the Burden Assessment Scale is an internally consistent and

conceptually meaningful tool that is useful for research and program evaluation. The BAS is a brief, easily administered measure that requires minimal interviewer training for research studies and also can be reliably self-administered. Most important, it captures the concept of burden through distinct objective and subjective dimensions and does not confound these caregiver consequences with the predictors of burden, such as disruptive behaviors and caregiving activities.

The data from the DMH&H study indicate that total burden scores can be used to evaluate program effectiveness. Additionally, the stability of the factor structure (for four of the five factors) suggests that objective and subjective burden have distinguishable and similar components even when the BAS is used with different populations of families with seriously mentally ill members and with different methods of administration.

The utility of the BAS should be determined empirically through additional research. Horwitz and Reinhard are currently using the BAS in a two-year study of informal supports to seriously mentally ill persons discharged from a New Jersey state psychiatric hospital. Analyses of these data will provide another opportunity to clarify the factor structure of the BAS, particularly in relation to the way burden may be perceived by different family members (e.g., parents and siblings).

From a systems perspective, the BAS offers a tool for assessing family members' burden related to serious mental illness and for measuring reductions in burden in relation to clinical and service interventions. The data suggest that the BAS measure has sufficient sensitivity, even among relatively homogeneous samples, to use burden as an outcome variable for program evaluation.¹ Future research might compare the impact of specific interventions on burden as well as examine change in burden over the course of illness and treatment. The data

¹Spanish version of the BAS, prepared by Dr. Carol I. Weiss, is available upon request.

TABLE 4
PREDICTORS OF CHANGES IN FAMILY BURDEN FROM ONE TO
SIX MONTHS FOLLOWING PROGRAM INTAKE

Predictors	Unstandardized beta (<i>b</i>)	Standard error (<i>SE</i>)	<i>T</i>
Number of concurrent service types (1-6)	2.40	0.87	2.76**
Number of single family consultations	0.14	0.07	2.01*
Initial family burden	0.56	0.10	5.60***
Age of ill family member	0.01	0.09	0.07
Diagnosis of schizophrenia ^a	-1.85	2.22	-0.83
Family participant is a mother ^a	-2.05	2.61	-0.78
Number of other family participants	-5.31	1.75	-3.04**
$R^2 = .47, F = 12.6***$			

^aCoded yes = 1, no = 2.

* $p < .05$. ** $p < .01$. *** $p < .001$.

presented here indicate that the BAS can be a useful tool for exploration of these and related issues.

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APPENDIX

BURDEN ASSESSMENT SCALE

I am going to read a list of things which other people have found to happen to them because of their relative's illness. Would you tell me to what extent you have had any of the following experiences in the past six months.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

Because of (name's) illness, to what extent have you:

_____ 1. Had financial problems

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 2. Missed days at work (or school)

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 3. Found it difficult to concentrate on your own activities

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

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

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 5. Cut down on leisure time

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>9</u>
Not at all	A little	Some	A lot	NA

_____ 6. Found the household routine was upset	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 7. Had less time to spend with friends	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 8. Neglected other family members' needs	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 9. Experienced family frictions and arguments	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 10. Experienced frictions with neighbors, friends, or relatives outside the home	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 11. Became embarrassed because of (name's) behavior	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 12. Felt guilty because you were not doing enough to help	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 13. Felt guilty because you felt responsible for causing (name's) problem	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 14. Resented (name) because s/he made too many demands on you	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 15. Felt trapped by your caregiving role	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 16. Were upset about how much (name) had changed from his or her former self	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 17. Worried about how your behavior with (name) might make the illness worse	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 18. Worried about what the future holds for (name)	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA
_____ 19. Found the stigma of the illness upsetting	<u>1</u> Not at all	<u>2</u> A little	<u>3</u> Some	<u>4</u> A lot	<u>9</u> NA