

## ORIGINAL PAPER

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## Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory

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**Abstract** The aim of this study was to develop a practical, comprehensive, and valid self-report measure of the experience of caring for a relative with a serious mental illness. The notion of caregiver 'burden' was rejected; instead caregiving was conceptualised within a 'stress-appraisal-coping' framework. A 66-item version of the Experience of Caregiving Inventory (ECI) was derived from analyses of responses from 626 caregivers, and then tested on an independent sample of 63 relatives of patients with schizophrenia recently in acute care. The extent to which the ECI complied with the stress-coping model was tested, especially the degree to which it, in association with coping, predicted psychological morbidity in carers. Ten sub-scales with good internal consistency resulted from our analyses, eight negative (difficult behaviours; negative symptoms; stigma; problems with services; effects on the family; the need to provide backup; dependency; loss) and two positive (rewarding personal experiences; good aspects of the relationship with the patient). The ECI, in conjunction

with coping style, predicted a large proportion of the variance in the General Health Questionnaire (GHQ). We concluded that the ECI taps salient dimensions of caregiving distinct from, although linked with, coping and psychological morbidity. It has potential as a useful outcome measure for interventions aimed at promoting caregiver well-being.

Increasing recognition of the key role of informal caregivers of severely mentally ill persons in community care (Creer and Wing 1974; Hatfield 1978; Creer et al. 1982; Fadden et al. 1987) has provoked an interest in developing instruments to measure the difficulties they encounter (Platt 1985; Schene 1990). Our aim was to devise a self-report measure of caregiving, covering a broad range of experiences, that is easy to administer, acceptable to respondents, and with solid construct as well as face validity.

When we commenced our work in 1990, we concurred with Schene (1990) in his detailed review of instruments for serious mental illness that many problems are still to be overcome in developing a satisfactory measure of caregiving. All instruments are based on 'burden', a difficult notion to operationalise. None have been developed within an explicit theoretical framework of caregiving. A recent review of 21 instruments, some unpublished (Schene et al. 1994), indicates that 'burden' still remains the core. We abandoned 'burden' as the basis of a caregiver measure for reasons we give below. Instead, we worked within a 'stress-appraisal-coping' framework. Although a similar approach has been adopted for carers in dementia (Barush 1988), this has not been done for severe mental illness. This method also enabled us to deal with the knotty issue of validation. There is no obvious 'gold standard' for caregiver 'burden'; carers tell us how they feel and we

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must accept their testimony. Our solution was to validate the instrument by examining its construct validity within the theoretical model employed.

### Conceptualising the experience of caregiving: the notion of 'burden'

A concept of caregiver 'burden' able to facilitate research has proved elusive (Platt 1985; Schene 1990). According to the Concise Oxford Dictionary, 'burden' means "that which is borne; a load". Applied to carers of a relative with a mental illness, 'burden' implies a description of that which is borne. This has been termed 'objective burden' - "anything that occurs as a disrupting factor in family life owing to the patient's illness" (Hoenig and Hamilton 1966). Platt (1985) further defines it as a "disruption to family/household life which is potentially verifiable and observable". However, there is also a sense of a load that is heavy or oppressive; hence 'subjective burden' - the feeling that a burden is being carried.

While apparently straightforward, the notion of 'burden' has led to problems in operationalisation. The 'objective' aspects are seen to relate to, for example, effects on work, social life, leisure activities, household routine, finances, and interactions within and beyond the family. Its estimation has two components - first that a disruption has occurred in the caregiver's 'normal' life, and second, its attribution to the patient's illness. Expressed in this way, difficulties start emerging. How can we know what the carer might have been doing or what activities the family might have pursued had they not had an ill relative? Some 'normal' people have busy social lives, some have little or no social life. In the case of the latter, this might be seen as connected with the demands of a relative's mental illness, but might have occurred anyway. Often, by the time of assessment, the illness is chronic, and how the carer's life was in the past as a possible point of comparison with now is difficult to gauge. Families also change necessarily in activities and relationships through the life cycle; such normal changes could be ascribed erroneously to the illness. Even if restrictions in the carer's life occur coincident with a relative's illness, can they confidently be attributed to that illness? Thus, judgments in measuring 'objective burden' are largely based on hypothetical situations, a quite inadequate basis for a research tool. Matters are compounded by the carer usually being the research informant, so the description of disruptions and their attribution may be influenced by subjective factors, not least by how 'burdensome' they find the caring role.

'Subjective burden' also presents problems. It has generally been measured in one of two ways. In the first, it is directly tied to previously assessed 'objective burden' as recounted by the carer (Platt 1986). Each symptom, difficult behaviour, or disruption is rated for

its burdensomeness. Thus, if an aspect of the caregiving experience is not rated as 'objective', neither can it be rated as 'subjective'. In the second approach, a global rating is made of how distressed by the patient's illness the carer feels, or it is made along a few general dimensions (Hoenig and Hamilton 1966; Pai and Kapur 1981). The former not only rests on the fragile notion of 'objective burden', but it also excludes distress arising from wholly 'non-objective' aspects of caregiving, like grief over the loss of the person the patient once was or promised to become. The second approach suffers from a lack of specificity with little indication of how the distress might be connected with caregiving. Moreover, there is usually no reason to believe that what is termed 'subjective burden' differs significantly from the psychological morbidity measured by established instruments such as the General Health Questionnaire (GHQ).

Further problems with the concept of caregiver 'burden' are its failure to recognise possible rewarding aspects of caring (Bulger et al. 1993) and the fact that it does not readily locate itself within a psychological or social theory that addresses determinants, mediating influences, or outcomes. In most, if not all existing measures, items have built-in assumptions that the disruptions rated by the caregiver are caused by the patient and that these disruptions are the cause of the caregiver's distress. Thus, caregiving is confounded by prejudged determinants and outcomes.

### Stress-coping framework

To overcome these limitations we investigated caregiving within a 'stress-coping' paradigm (Lazarus and Folkman 1984). A simple model is illustrated in Fig. 1. The caregiving experience is conceptualised here as an *appraisal* of its demands. This refers to the salience of threatening, as well as positive aspects of the caregiving role. The patient's illness, behaviours, disabilities, and perceived disruptions of the carers' life are the *stressors* appraised by the carer. *Mediating factors*, such as the carer's personality, quality of family relationships, or degree of social support may influence the appraisal. *Outcomes* in terms of psychological or physical morbidity are regarded as the result of an interaction between the appraisal and the carer's *coping* strategies (the cognitive and behavioural efforts aimed at controlling the demands imposed by the stressor). Since carers are not patients, it is important that outcomes should also be construed in terms of well-being, not merely morbidity. A point of departure from most studies of coping is noteworthy. A specific or acute stressor is not being studied, but a constellation of events related to caring for a mentally ill person over a specified period of time, in this case a month. How appraisal and coping vary over time in this context remains to be determined.



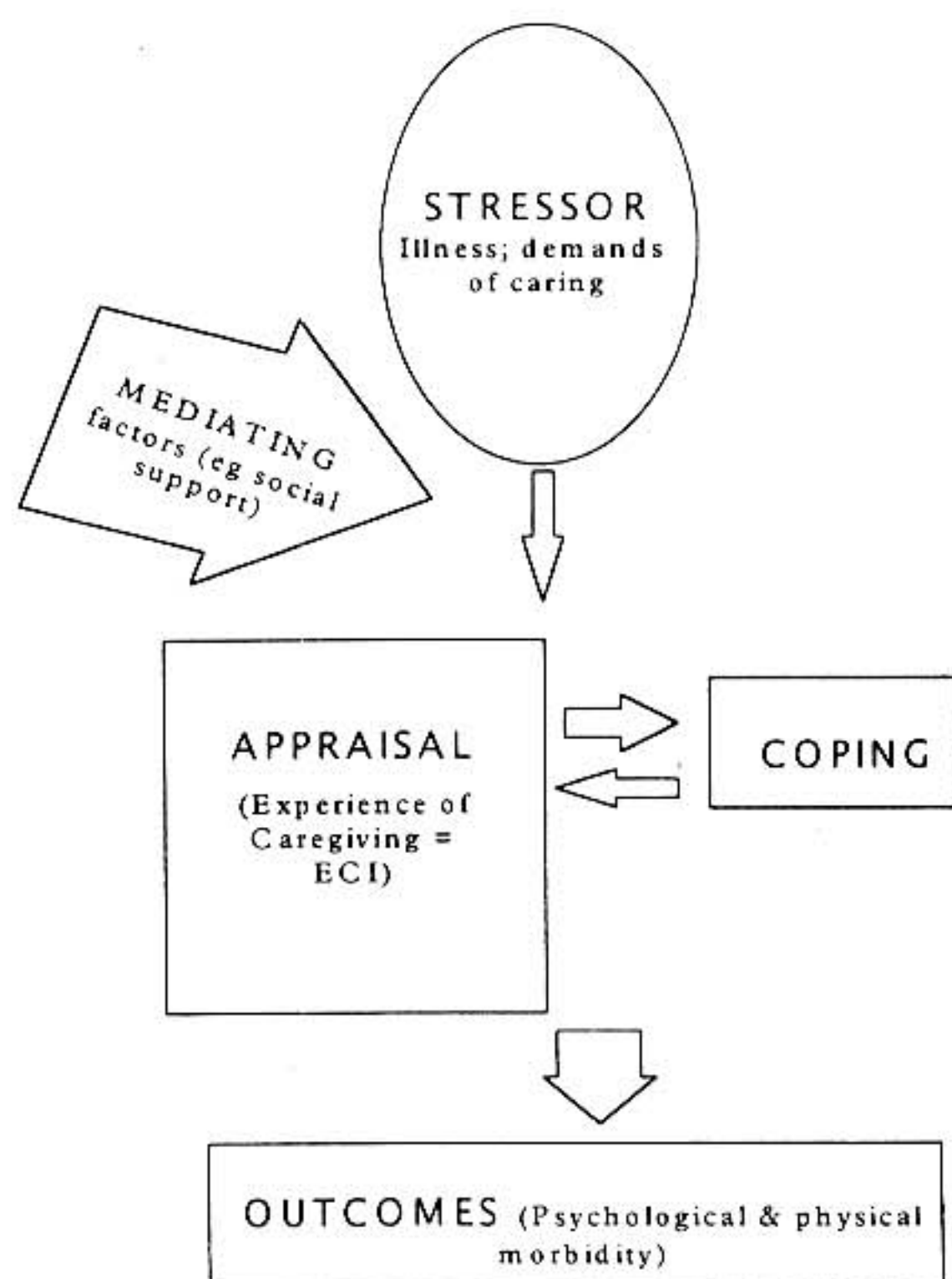


Fig. 1 A 'stress-coping' model of caregiving

Our instrument, the Experience of Caregiving Inventory (ECI), is a measure of appraisal. Its construct validity was tested by examining the extent to which it related as predicted to the stress-coping model. Since the model is interactive or circular (for example, appraisal affects coping and vice-versa) so cross-sectional data provide a limited perspective on the processes involved. Nevertheless, it is possible to examine the strength of association between factors and their consistency with the model. Furthermore, since appraisal lies within the 'subjective' domain, a self-report inventory is appropriate; this also offers practical advantages if the measure is to be used routinely.

### Aims of the study

The aims of the study were as follows:

1. To develop a measure of caregiving, conceptualised as the carers's appraisal.
2. To test the construct validity of the ECI within the stress-coping model described above. We hypothesised that the ECI would be substantially predicted by a combination of carer, care-recipient, and mediating factors, and that in turn it would, in combination with coping, significantly predict caregiver morbidity and well-being.

The report is divided as follows:

1. Construction of the ECI.

2. Validation of the ECI, which included: (a) an examination in a sample of 359 carers of the extent to which the ECI and coping predicted psychological morbidity. (b) a replication and fuller examination of the caregiving model in a further, *independent* sample of 63 carers of patients with schizophrenia recently discharged from hospital. Details were collected about the patient's illness, possible mediating factors (social support, family relationships, life events), as well as a broad range of carer outcome measures (GHQ, ratings of health, visits to a general practitioner (GP), well-being).

Table 1 summarises the stages of the study and steps in developing the measure.

### Construction of the instrument

#### Methods

We collaborated with two major self-help organisations, the Schizophrenia Fellowship of Victoria (SFV) and the Association of Relatives and Friends Experiencing Mental Illness (ARAFEMI). One hundred and twenty relatives were interviewed individually and in groups by two research assistants. A range of prompts was used to elicit and clarify their experiences, beginning with: "What is it like for you looking after your mentally ill relative?" Each reply was recorded on a 'white board', while new themes were elicited by asking all participants how their experiences differed from those already raised. Items from existing 'burden' measures were examined later. Hundreds of statements were collated. We then removed redundant or idiosyncratic items and rephrased others for clarity.

The set of items, now 130, was then presented to other relative groups for comment, resulting in further rephrasing. The instrument was named the Experience of Caregiving Inventory (ECI). Each ECI item was presented twice in parallel questionnaires. On the first presentation the respondent was asked "during the last month, how often have you thought about...", and in the second, "during the past month, how much have you been upset by..." The first attempted to assess the salience of thoughts and the second, the degree of distress.

The 130-item version was then distributed to 600 relatives by post or by hand. Two-thirds were a random sample from the membership lists of SFV and ARAFEMI, the remainder were carers of patients attending a psychiatric hospital or mental health clinic. In all, 267 completed questionnaires were returned. A preliminary analysis of the responses was carried out using a principal components analysis (PCA) to identify the major dimensions. The SPSS-Factor program was used with varimax rotation. Loadings were examined on each principal component treated as a factor. We recognised the limitations posed by a large number of items and a relatively small sample, but our aim at this stage was to explore the main dimensions of the instrument and to eliminate isolated items. Fifteen item sets emerged, each having three or more items loading 0.4 or higher on only one factor and separated by at least 0.1 from its loading on any other.

As a result of these analyses the number of items was reduced to 87. Since the correlation between frequency of thoughts and the degree of upset was greater than 0.9 for all items, we decided to use only the former as this seemed susceptible to clearer definition and was consistent with the underlying goal to measure appraisal rather than emotion.

A further 500 questionnaires, now with 87 items, were distributed to a second random sample of carers in the self-help organisations and to carers of patients at the hospital, with 359 being returned. The PCA analyses reported in this study derived from the entire population of 626 carers. This larger sample was used because of the large



**Table 1** Stages in developing the Experience of Caregiving Inventory (ECI; PCA Principal components analysis, GHQ General Health Questionnaire)

Instrument construction	
1. Generation of questionnaire items	Interviews with 120 relatives; clarification of statements; examination of existing measures → 130-item version
2. First survey group	130-item version completed by 267 respondents Preliminary PCA; exclusion of items not loading on first 15 factors → 87-item version
3. Second survey group	87-item version completed by 359 respondents Subjects also completed measures of coping and GHQ
4. Analysis of 87-item version	Carried out on entire group of $(267 + 359) = 626$ carers PCA and scale reliability analyses; 10 scales generated → final 66-item version
5. ECI completed by a 'clinic' group of carers	Further <i>independent</i> group of 63 carers of schizophrenia patients recently discharged from hospital completed final 66-item version. Also completed measures of stressor and mediating variables in addition to coping, GHQ, well-being, and health ratings
Validation	
6. Validation of 66-item ECI within 'stress-coping' model	a) Second survey group ( $n = 359$ ): prediction of psychological morbidity b) Independent clinical sample ( $n = 63$ ): prediction of psychological morbidity; also, prediction of ECI by stressors and mediating variables

number of questionnaire items. We noted the possible influence deriving from two forms with different numbers of questions. However, comparison of the two groups showed, on visual inspection, a similar pattern of loadings on both occasions for at least the first eight factors. The results were also tested for scale reliability. Separate versions of the ECI were prepared for male and female patients.

In the statistical analyses, the principal components extraction procedure in SPSS-Factor was used. Scale reliability – Cronbach alpha coefficient, item-scale, and inter-item correlations – was examined using SPSS-Scales.

## Results

### Characteristics of caregivers and patients

Of the 626 relatives surveyed, 66% were female; the mean ( $\pm$  SD) age was  $53 \pm 30$  years; 60% were from self-help organisations, the rest were recruited through hospitals and clinics; 68% were married, 13% were widowed, and 17% were divorced; 61% were living with the patient. The patients' mean age was  $33 \pm 11$  years; the mean duration of their illness was  $11.5 \pm 8.8$  years; the mean number of admissions was  $4.4 \pm 3.3$ ; the mean number of weeks in hospital in the previous 6 months was  $2.5 \pm 5.1$ ; 80% had a diagnosis of schizophrenia. The relationship of carer to patient was: mother, 60%; father, 11%; spouse, 16%; sister, 9%. Nineteen percent of carers had a university education, 23% had further education at a college, and 58% had secondary education only.

### ECI characteristics

The 87-item ECI was subjected to a PCA ( $n = 626$ ) to determine its major dimensions. Median substitution was used for missing data, which ranged between 2 and 6% per item. This yielded 14 factors with eigenvalues greater than 1.0, and accounted for 60% of the total variance. After a preliminary inspection of results, PCAs were run for 8-, 10-, and 12-factor solutions. Many distinct dimensions emerged, the best coverage requiring 10 scales. These scales were constructed by selecting items as follows: loading greater than 0.4 on a PCA factor, having a loading at least 0.1 greater than on any other factor, and having at least 4 items fulfilling these criteria. A maximum of 8 items per scale was adopted. The final scales and factor loadings are shown in Table 2. The rejected 8-factor solution did not separate 'difficult behaviours' from 'negative symptoms', or the two 'positive' scales. The 12-factor solution separated the 'effects on the family' into two not easily distinguished factors, and produced an additional patient behaviour factor with only 3 items. In the 10-factor solution, two scales had more than 8 items. The 8 items loading highest were selected. The remaining factors had 5-8 items, all of which were selected.

The 10 scales were then checked for reliability. Reliability coefficients are also shown in Table 2, as are the frequencies with which items were 'thought about' by the carer 'often' or 'always'. Each scale had a satisfactory Cronbach alpha coefficient. There were 8 'negative' and 2 'positive' scales. While the caregiving



**Table 2** Experience of Caregiving Inventory: scale characteristics; frequency of endorsement of items

Difficult behaviours (Cronbach alpha 0.91)		Factor loading	Item-scale correlation	'Often' or 'always' (%)
53	Moody	0.64	0.68	43
54	Unpredictable	0.70	0.76	42
61	Irritable	0.75	0.75	30
62	Inconsiderate	0.68	0.78	31
63	Behaving in a reckless way	0.70	0.69	17
64	Suspicious	0.59	0.68	26
65	Embarrassing in appearance	0.57	0.65	20
66	Behaving in a strange way	0.63	0.69	25
Negative symptoms (Cronbach alpha 0.89)				
55	Withdrawn	0.62	0.70	38
56	Uncommunicative	0.62	0.76	38
57	Not interested	0.69	0.77	47
58	Slow at doing things	0.70	0.70	57
59	Unreliable about doing things	0.8	0.68	46
60	Indecisive	0.60	0.60	53
Stigma (Cronbach alpha 0.82)				
1	Covering up his illness	0.82	0.64	16
2	Feeling unable to tell anyone about his illness	0.81	0.69	18
27	Feeling unable to have visitors at home	0.42	0.51	21
38	The stigma of having a mentally ill relative	0.69	0.67	19
39	How to explain his illness to others	0.54	0.57	26
Problems with services (Cronbach alpha 0.90)				
10	How mental health professionals do not take you seriously	0.67	0.68	27
16	Dealing with psychiatrists	0.71	0.68	29
26	How to deal with mental health professionals	0.76	0.74	30
36	How health professionals do not understand your situation	0.71	0.73	32
42	How to make complaints about his care	0.69	0.67	21
50	Finding out how hospitals or mental health services work	0.71	0.69	29
51	Doctor's knowledge of services available	0.64	0.63	31
52	Difficulty getting information about his illness	0.67	0.61	25
Effects on family (Cronbach alpha 0.82)				
21	How family members do not understand your situation	0.58	0.54	34
28	How he gets on with other family members	0.52	0.57	38
30	How family members do not understand the illness	0.58	0.58	38
40	Others leaving home because of the effects of the illness	0.41	0.53	14
46	The effects of the illness on children in the family	0.49	0.53	34
47	The illness causing a family breakup	0.49	0.60	21
49	How his illness affects special family events	0.52	0.61	34

Table 2 (Continued)

Need to backup (Cronbach alpha 0.76)		Factor loading	Item-scale correlation	'Often' or 'always' (%)
3	Has difficulty looking after money	0.58	0.35	44
4	Having to support him	0.57	0.54	32
15	The effect on your finances	0.45	0.49	28
29	Backing him up when he runs out of money	0.61	0.58	36
41	Setting him up in accommodation	0.46	0.45	35
8	Him keeping bad company	0.47	0.46	21
Dependency (Cronbach alpha 0.74)				
9	Unable to do the things you want	0.54	0.52	34
11	His dependence on you	0.68	0.54	56
12	Helping him to fill in the day	0.52	0.51	40
17	He's always at the back of your mind	0.41	0.42	75
45	Feel unable to leave him home alone	0.46	0.50	31
Loss (Cronbach alpha 0.79)				
5	What sort of life he might have had	0.51	0.58	61
6	His risk of committing suicide	0.53	0.56	21
18	Whether you have done something to make him ill	0.41	0.46	16
24	He thinks a lot about death	0.55	0.53	21
25	His lost opportunities	0.49	0.54	58
31	How he attempts to harm himself	0.55	0.54	12
37	Whether he will ever get well	0.47	0.47	61
Positive personal experiences (Cronbach alpha 0.86)				
7	I have learnt more about myself	0.65	0.61	22
8	I have contributed to others' understanding of the illness	0.70	0.63	31
20	I have become more confident dealing with others	0.73	0.67	25
23	I have become more understanding of others with problems	0.68	0.64	57
32	I have become closer to some of my family	0.64	0.55	23
33	I have become closer to friends	0.66	0.56	17
43	I have met helpful people	0.59	0.51	33
44	I have discovered strengths in myself	0.75	0.71	31
Good aspects of relationship (Cronbach alpha 0.82)				
13	I have contributed to his well-being	0.58	0.49	54
14	He makes a valuable contribution to the household	0.63	0.57	19
19	He has shown strengths coping with his illness	0.52	0.56	35
22	He is good company	0.61	0.65	22
34	I share some of his interests	0.64	0.62	20
35	I feel useful in my relationship with him	0.61	0.64	43



dimensions were distinct, intercorrelations between the negative scales were around 0.5, as was the correlation between the two positive scales. The final version of the ECI comprised the 66 items incorporated in the scales. The analyses in the validation described below are based on this version.

At this point a few comments concerning relationships between carers' demographic features and the ECI scales are appropriate. A significant sex difference occurred, with males scoring higher on 'negative symptoms', 'backup', and 'problems with services' ( $P = 0.0002$ ). No difference occurred between mothers and fathers, but spouses scored higher on 'loss' ( $P = 0.001$ ) and 'backup' ( $P = 0.002$ ) than parents. Where carers lived with the patient, they scored higher on 'dependency' and 'negative symptoms' than those living away ( $P = 0.0002$ ). No significant interactions were found between these variables. Where differences were found they were small in magnitude (around 5%) and of questionable practical relevance. The large  $p$  values reflected the large group sizes. There were no significant differences in ECI scores between carers of those with a diagnosis of schizophrenia versus those 20% with other disorders.

### Validation of the ECI

As explained in the Introduction, validation was based on the construct validity of the ECI within a stress-coping model. Two samples of carers were studied:

(A) The second survey group of carers ( $n = 359$ ; see Table 1). In this group measures of coping and the GHQ were administered. The extent to which the ECI (in its final 66-item form) in combination with coping predicted GHQ scores was tested.

(B) An *independent*, further group of 63 carers of patients with schizophrenia recently discharged from hospital. This provided an independent replication of the analysis and also a fuller examination of the caregiving model since measures were also taken of the patient's illness, possible mediating factors (social support, family relationships, life events), as well as a broad range of carer outcome measures (GHQ, ratings of health, visits to a GP, well-being).

These 63 carers were recruited for a controlled study of an intervention aimed at reducing morbidity and enhancing well-being in a consecutive series of relatives of patients with schizophrenia discharged from hospital 6 weeks earlier (Szmukler et al. 1996). The carers' mean age was  $46 \pm 15$  years, the patients',  $31 \pm 12$ . The mean duration of illness was  $8.4 \pm 9.0$  years and the mean number of previous admissions was  $4.0 \pm 3.7$ . A major difference between this sample and the larger 'survey' sample was in GHQ scores (survey group,  $6 \pm 9$ ; 'clinic' sample,  $22 \pm 13$ ). There were also differences on some ECI scales, with the survey group scoring significantly

higher on 'difficult behaviours', 'negative symptoms', 'effects on the family', and the need for 'backup'. However, the aim of the validation was to examine the congruence with the 'stress-coping' model of the relationships between variables within each group of subjects.

### Methods

Measures of coping and psychological morbidity were completed by carers in both groups. These were:

#### *Coping measures*

*Mastery.* Mastery (Pearlin and Schooler 1978) measures the degree to which a subject is confident in his ability to help himself and to manage both expected and unexpected circumstances, e.g. "I have little control over the things that happen to me", "I can do just about anything I really set my mind to"; "There is really no way I can solve some of the problems I have". The seven-item scale has good internal reliability, and in one study has been found to be the most powerful predictor of distress in relatives of discharged psychiatric patients (Noh and Turner 1987). Carers rated mastery for the previous month.

*Ways of Coping (WOC).* WOC, adapted from the Ways of Coping Checklist of Folkman and Lazarus (1985) by MacCarthy and Brown (1989), covers cognitive and behavioural coping strategies for stressful events. This shorter 28-item version was chosen in order to avoid overloading respondents. The period covered was the past month, and the stressful events were those associated with having an ill relative.

We used our large sample to replicate the subscales derived by McCarthy and Brown on a smaller group. (Space does not permit detailed presentation of the results here but these can be obtained from the first author). Four scales emerged using similar criteria to those presented for the ECI: (1) 'practical coping' (Cronbach alpha 0.79): e.g. "tried to work out what the problems were and what makes them better or worse", "asked professionals, friends, or relatives for practical advice and information", "asked someone to do something practical about the problem"; (2) 'emotional coping' (alpha 0.74): e.g. "took my feelings out on something or someone", "thought about practical things but put off doing things about it", "criticised or blamed myself", "avoided other people"; (3) 'detachment' (alpha 0.72): e.g. "turned my attention to other activities that I could do on my own", "tried to step back from the situation", "tried not to think about what was happening"; (4) 'faith/hope' (alpha 0.62): e.g. "told myself I had other things in my life to be thankful for", "hoped a new treatment would become available", "prayed".

We followed the suggestion of Vitaliano et al. (1987) to use relative scores (the percentage of total efforts for each coping type) instead of raw scores (the absolute score on each scale). Preliminary analyses using raw scores accorded with their observations that coping styles were less clearly differentiated since many respondents scored highly on all scales. For example, the correlation between 'practical' and 'emotional' coping (raw scores) was  $+0.31$ , compared with  $-0.47$  for relative scores. Since the sum of the relative scores is 1, a conditioned matrix in regression analyses allows only three scales to be entered. 'Faith/hope' was excluded.

#### *Psychological morbidity*

*The GHQ.* The GHQ (Goldberg and Hillier 1979) is a screening instrument covering a range of psychiatric symptoms - anxiety,



depression, somatic, and social dysfunction. The 28-item scaled version was used and scored in a Likert fashion (0–3).

### Stressors

Additional measures were administered to the 'clinic' group only as follows:

*Inventory of caregiving activities* Carers were asked whether they helped the patient with a range of caregiving activities: getting patient out of bed, dressing, personal hygiene, organising meals, cleaning up, shopping, managing finances, finding employment, daily activities, medication, assisting with appointments, organising health services, and social services. They then estimated the hours per week devoted to each. Since this proved too difficult for most carers it will not be considered further. The score given was a sum of the number of caregiving activities endorsed by the carer.

*Life Skills Profile (LSP)*. The LSP (Rosen et al. 1989) is a questionnaire measure of social impairment and disability associated with schizophrenia that is completed by a person who knows the patient well. Five subscales can be identified: self-neglect, turbulence, seclusion, inappropriateness, and irresponsibility. Each caregiver rated the patient; the LSP was also completed by the patient's case manager where there was one (32 cases). Only the total score was used.

### Mediating factors

These measures were administered to the 'clinic' group only.

*Family Environment Scale (FES)*. The FES (Moos and Moos 1980) is a widely used self-report measure of family functioning comprising three major dimensions - relationships, personal growth, and system maintenance. The short form was used. We focused on the first dimension, examining the subscales for 'cohesion', 'expressiveness', and 'conflict'. A single 'family relations index' was derived by subtracting 'conflict' from the sum of 'cohesiveness' and 'expressiveness'.

*Provision of Social Relationships (PSR)*. The PSR (Turner et al. 1983) has 15 items dealing with perceived support from family and friends. It has good internal consistency and concurrent validity with the Kaplan Scale of Social Support.

*List of Threatening Experiences (LTE)*. The LTE (Brugha et al. 1985) is a catalogue of 12 life event categories likely to carry considerable long-term threat as rated in previous community studies.

Two of the 12 items might have been confounded with the patient's illness.

### Outcomes

In addition to the GHQ, the following were also administered to the 'clinic' group only.

*Positive and Negative Affect Scale (PANAS)*. The PANAS (Watson et al. 1988) consists of two scales measuring positive and negative affect, the dominant dimensions of mood. 'Positive affect' reflects the extent to which a person feels enthusiastic, active, and alert. 'Negative affect' is a dimension of distress and unpleasurable engagement. The two scales are not usually correlated. Our subjects were asked to rate mood over the past month. The 'positive affect' scale was considered a measure of 'well-being'.

*Physical health*. Physical health was rated on a self-rating four-point scale, from 'excellent' to 'poor' (1–4). The subjects also completed a self-report concerning the number of contacts with their GP in the previous 6 months for their own health.

### Statistical analyses

Testing the 'stress-coping model', multiple regression procedures were used to examine:

- (1) In the second survey group ( $n = 359$ ), the extent to which the ECI in combination with coping predicted GHQ scores.
- (2) In the 'clinic' group, the extent to which the ECI in combination with coping not only predicted GHQ scores, but also negative affect, positive affect, physical health self-ratings, and visits to the carer's GP for their own health. Secondly, the extent to which the stressor (LSP, inventory of caregiving activities) and mediating factors (family relations index, social support, life events) predicted ECI scores.

## Results

### Prediction of psychological morbidity by the ECI and coping in survey group

A multiple regression was performed to measure the prediction of GHQ scores by the ECI and coping in the group of 359 respondents. Independent variables were entered in the following order: ECI, 'mastery', then WOC. Mastery was entered before coping because it is the simpler measure. Results are presented in Table 3.

**Table 3** Prediction of GHQ in 'survey' group. Dependent variable: GHQ

Step	Independent variable	Zero-order correlation	b	SE	Beta	$R^2$	$R^2$ change	P value
1	ECI (neg)	0.40**	0.078	0.011	0.315**	0.24		0.000
2	Mastery	0.40**	0.253	0.075	0.16**	0.30	0.06	0.000
3	Ways of Coping							
	'Practical'	0.13*	0.363	0.100	0.21**			
	'Emotional'	0.45**	0.830	0.110	0.42**			
	'Detached'	0.09	0.325	0.092	0.19**	0.40	0.10	0.000

Final:  $R = 0.63$ ;  $R^2 = 0.40$ ; adjusted  $R^2 = 0.39$ ,  $F(5, 352) = 46.0$ ;  $P = 0.000$

\* $P < 0.05$ ; \*\* $P < 0.001$



**Table 4** Prediction of GHQ in 'clinic' group. Dependent variable: GHQ

Step	Independent variable	Zero-order correlation	b	SE	Beta	R <sup>2</sup>	R <sup>2</sup> change	P value
1	ECI (neg)	0.62**	0.160	0.038	0.43**	0.39		0.000
2	Mastery	0.52**	0.707	0.283	0.29*	0.48	0.09	0.003
3	Ways of Coping							
	'Practical'	0.19	0.085	0.345	0.03			
	'Emotional'	0.50**	0.670	0.370	0.24			
	'Detached'	0.09	0.622	0.379	0.18	0.55	0.07	0.046

Final:  $R = 0.74$ ;  $R^2 = 0.55$ ; adjusted  $R^2 = 0.51$ ,  $F(5, 56) = 13.5$ ;  $P = 0.000$

\* $P < 0.05$ ; \*\* $P < 0.001$

**Table 5** Prediction of 'Positive affect' in 'clinic' group. Dependent variable: Positive and Negative Affect Scale (PANAS) - 'positive affect'

Step	Independent variable	Zero-order correlation	b	SE	Beta	R <sup>2</sup>	R <sup>2</sup> change	P value
1	ECI (pos)	0.30*	0.184	0.120	0.22			
	ECI (neg)	0.14	0.024	0.038	0.10	0.17		0.000
2	Mastery	0.32*	0.059	0.242	0.03	0.19	0.02	0.203
3	Ways of Coping							
	'Practical'	0.36**	0.024	0.289	0.02			
	'Emotional'	0.44**	0.615	0.318	0.34			
	'Detached'	0.27*	0.312	0.334	0.14	0.28	0.09	0.108

Final:  $R = 0.52$ ;  $R^2 = 0.28$ ; adjusted  $R^2 = 0.20$ ,  $F(6, 55) = 3.49$ ;  $P = 0.005$

\* $P < 0.05$ ; \*\* $P < 0.001$ ; \*\*\* $P < 0.001$

The sum of the eight ECI negative scales (ECI-neg) was used for simplicity; the outcome was very similar when the individual ECI scales were entered as a block. The ECI alone accounted for 24% of the variance, 'mastery' added 6%, and WOC, another 10%. Together, ECI and coping accounted for just under 40% of the variance in GHQ.

Further testing of the 'stress-coping' model in the 'clinic' sample

#### *The ECI and coping as predictors of morbidity and well-being*

Prediction of GHQ scores was examined exactly as for the survey group. The results (Table 4) were very similar except that ECI and 'mastery' accounted for greater percentages of the variance in the GHQ, with WOC adding less. The combination accounted for 51% of the variance. The result for the PANAS 'negative affect' was almost identical to the GHQ, the combination accounting for 49% of the variance ( $R = 0.72$ ;  $R^2 = 0.52$ ; adjusted  $R^2 = 0.49$ ;  $p < 0.0000$ ).

The same predictor variables were entered for self-ratings of physical health. ECI-neg explained 11% of the variance, 'mastery', another 16%, and WOC another 5% (total  $R^2 = 0.33$ ; adjusted  $R^2 = 0.27$ ;

$p = 0.0004$ ). A similar analysis for number of GP visits in the previous 6 months for the carer's health found that ECI-neg explained 14% of the variance ( $R^2 = 0.16$ ; adjusted  $R^2 = 0.14$ ;  $p = 0.002$ ), but coping made no significant further contribution.

Next, prediction of 'positive affect' on the PANAS was examined (Table 5). ECI-pos and ECI-neg scales were entered together, explaining 17% of the variance. 'Mastery' did not contribute significantly, but WOC added 9%.

**Prediction of ECI scores.** We first examined the contribution to the negative ECI scale of carer's age and sex; patient's age, sex, duration of illness, and number of past admissions. Together they accounted for a mere 2% of the variance and will not be considered further.

We next examined the prediction of ECI scores by the key 'stressor' variables ('inventory of caregiving activities', carers' rating of patient's LSP) and the putative mediating variables (family relationships, social support, and life events). Variables were entered in the order presented above. (The case manager's LSP rating accounted for only 2% of the variance in ECI-neg and was omitted since it reduced the total number of carers to 32). Forty-four percent of the variance of ECI-neg was explained in total, with the major contributions coming from the LSP and social support (Table 6).



**Table 6** Prediction of ECI in 'clinic' group. Dependent variable: ECI negative scale

Step	Independent variable	Zero-order correlation	b	SE	Beta	R <sup>2</sup>	R <sup>2</sup> change	P value
1	Caregiving inventory	0.28*	0.717	1.238	0.06	0.08		0.030
2	Life Skills Profile	0.57***	0.823	0.217	0.42***	0.34	0.26	0.000
3	Family relations index	-0.34**	-1.770	1.466	-0.13	0.37	0.03	0.090
4	Social relations support	-0.49***	-1.324	0.671	-0.25*	0.46	0.09	0.004
5	Life events	0.37**	4.507	2.958	0.17	0.49	0.03	0.134

Final:  $R = 0.70$ ;  $R^2 = 0.49$ ; adjusted  $R^2 = 0.44$ ,  $F(5, 52) = 9.90$ ;  $P = 0.000$

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$

Attempts to predict the ECI positive scales were unsuccessful. Less than 1% of the variance of the ECI-pos score was predicted by the combination of variables used in the ECI-neg regression above.

## Discussion

A self-report inventory of the experience of caregiving was developed that is not constrained by the built-in assumptions around the notion of 'burden'. Our method ensured strong face validity, the content being based on a large number of relatives' reports. The ECI was easy to administer, took about 10–15 min to complete, and, based on carers' feedback, was readily accepted. When we examined the ECI's relationship to relevant variables in a stress-coping model to test its construct validity; it behaved as hypothesised.

As found by others, the data indicated that the experience of caregiving is multidimensional (Schene et al. 1994). Ten relatively independent dimensions were identified, eight negative in valence ('difficult behaviours', 'negative symptoms', 'stigma', 'problems with services', 'effects on family', 'need to backup', 'dependency', and 'loss') and two, positive ('positive personal experiences' and 'good relationship with the patient'). Areas were covered that have not been prominent in other instruments - the experience of loss and problems with mental health professionals. Positive attributes of caring also emerged, supporting the findings of Bulger et al. (1993); these are noteworthy since a broader perspective on helping carers could include enhancing the positive aspects of caregiving, as well as reducing the negative.

The construct validity of the ECI within a 'stress-coping' model was examined in two populations, the first comprising carers predominantly associated with self-help organisations and the second, relatives of a consecutive series of patients with schizophrenia recently discharged from acute care. In both groups the ECI behaved as expected in terms of the model in predicting GHQ scores. The ECI and coping each

made significant contributions. In the 'clinic' group, with higher GHQ scores, the ECI accounted for a greater proportion of the variance in that variable. The results for the 'clinic' group suggested that the seven-item 'mastery' questionnaire may be as useful a measure of 'coping' in this context as the more complex 28-item WOC. The power of this variable, noted by Noh and Turner (1987), was replicated here. In their study, 'mastery' swamped the contribution from their ad hoc measures of 'objective' and 'subjective' burden, a result not replicated in our work. The combination of ECI-neg and 'mastery' accounted for 30–50% of the variance in the GHQ. The similar findings in the two groups attested to the robustness of the ECI's relationships.

The interpretation of the WOC questionnaire was complicated by the fact that, as stated earlier, respondents often score highly on more than one scale. Those with high 'absolute' scores on 'emotional' coping also tended to score highly on 'practical' coping. However, in terms of 'relative' scores, the two types of coping were negatively correlated. This may indicate that 'emotional' coping follows failed efforts at 'practical' coping.

ECI and coping also significantly predicted physical health ratings. Visits to GPs by carers were also significantly predicted by the ECI, but coping played little or no role. Overall, a similar pattern of relationships occurred for all of the 'outcome' variables.

The ECI also fitted the 'stress-coping' model in terms of its prediction by stressors, combined with mediating variables, at least the negative scales. The patient's behavioural problems as perceived by the relative and the degree of social support were the major influences. Family dysfunction as measured by the 'family relations index' of the FES did not contribute substantially, but this is a brief, not very comprehensive measure of the family. Expressed emotion (Kuipers and Bebbington 1988) might influence ECI more substantially, but is likely to be more directly coloured by the relative's difficulties in coping with the patient's illness. The case manager's LSP rating did not contribute significantly to the ECI score, and underscored our earlier com-



ments on the difficulty of achieving 'objective' ratings in studying caregiving. An inventory of activities with which the caregiver helped the patient was weakly related to the ECI.

The positive ECI scales were not predicted by the variables studied. In psychiatric research we are unaccustomed to examining positive aspects of functioning, so perhaps lack measures to determine key factors. We would do well to recall that caregivers of relatives with serious mental illnesses cope effectively with taxing, enduring problems. In attempting to measure their experiences we should resist a tendency to 'pathologise'; identifying and understanding good coping is as pertinent as detecting psychopathology. Perhaps influences such as affectionate relationships in both family of origin and family of creation, including a satisfying relationship with the patient before becoming ill, may all contribute, as may personal characteristics such as resilience and optimism.

What are the implications of our results for interventions aimed at helping carers? Psychological morbidity is related to caregiving through a negative cognitive appraisal and coping that lacks a sense of mastery or that involves emotionality or detachment. Well-being, as for example in positive affect, is associated with positive appraisal and less use of emotional coping. While the link between appraisal and coping is circular and mutually interactive, it may still be worth considering two elements in helping reduce caregiver morbidity and enhance well-being. Appraisal may be changed by exploring the personal meanings of the illness or by attempts at 'cognitive restructuring'. Coping may be enhanced by examining various coping strategies, seeking rewarding instances of 'mastery'. Other factors to be considered are the level of social support and, of course, symptom control.

The sensitivity of the ECI to changes in caregiving remains to be determined. The companion paper reporting on the outcome of a controlled intervention for the 'clinic' group shows that changes occurred over 6 months as patients recovered from an acute episode of care (Szmukler 1996).

In conclusion, the ECI provides a comprehensive description of the experience of caring for a relative with a serious mental illness. Conventionally, we conceive of distress in terms of typical symptoms as measured by instruments like the GHQ. However, as far as carers are concerned, there are aspects to their distress apart from the presence of 'neurotic' symptoms; the ECI tapped important ones. The instrument also appeared useful in engaging carers in a discussion of areas they found difficult, and may help in determining suitable targets for interventions aimed at enhancing well-being. The caregiving experience should represent an important outcome variable when programmes for patients with serious mental illness or their relatives are evaluated. To date, the study of caregivers has been rudimentary. We hope that our findings will help to

clarify the experience of caregiving and that the ECI will prove useful for its measurement.

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