

Stress is in the eye of the beholder: reconceptualizing the measurement of carer burden

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The development of community care policy and the inadequacies of professional responses to the needs of informal carers were described in an earlier paper. A qualitative analysis of carers' replies to a questionnaire survey demonstrated that the most potent stressors, contrary to what has previously been assumed, were linked more to subjective perceptions of events or circumstances than to the objective features of the events and circumstances themselves. This paper presents a quantitative analysis of data from the same survey which confirm the impressions gained from the analysis of the qualitative data. These findings prompt a reconceptualization of carer burden within a transactional model of stress, which is then considered as a basis for understanding how carers adapt to stress in their lives. Practice implications are assessed.

INTRODUCTION

The British government's philosophy of caring for dependency groups in the community and the reification of that policy from care in the community to care by the community has resulted in a burgeoning of research activity in this field. Twigg (1986) in reviewing the research literature on informal carers has identified two main themes: (a) the scope and extent of informal care, and (b) the burdens and costs that caring imposes on those providing care.

Research in the former area has demonstrated quite unequivocally that family members, usually female kin, provide most informal care (Equal Opportunities Commission

1982a,b, Bonny 1984, Henwood & Wicks 1984, Wicks & Henwood 1988) and following the publication of nationally representative data (Green 1988), reliable population estimates of the total number of informal carers are now available. Research in the latter area however has not been so conclusive and, despite an expanding knowledge base, important questions concerning the nature of carer stress and how it might be ameliorated remain unanswered (Parker 1985, Gwyther & George 1986). This paper endeavours to provide some tentative answers to these questions. Previous attempts to conceptualize and measure carer burden are briefly reviewed and it is suggested that they lack a theoretical cohesion and consistency. Using the results from a national sample survey of members of the

Association of Carers (now Carers National Association), carer burden is reconceptualized within a transactional model of stress and an empirical test for such a model is applied. The paper concludes with a consideration of the implications of the results for practice decisions in the field of informal care.

THE MEASUREMENT OF CARER BURDEN

Research highlighting the vulnerability of informal carers has demonstrated beyond any reasonable doubt that caring often has adverse effects on important domains of carers' lives. Such effects include poor physical and emotional health, impaired social and family life and reduced economic and employment opportunities. Whilst it has been suggested that social and personal life can be highly disrupted (Hooyman *et al* 1985, Wright 1986), most of the empirical evidence identifies a deterioration in emotional health as the most prevalent and pervasive consequence of caring (Hirschfield 1981, 1983, Equal Opportunities Commission 1982a, Cantor 1983, Worcester & Quayhagen 1983, Briggs 1983, Bowling 1984, Parker 1985, Brody 1985, Gwyther & George 1986, Bell *et al* 1987, Thompson 1987).

However, it is still not clear which factors precipitate these adverse consequences and which carer groups, if any, are the most affected. Dependency factors have been implicated by some (Sandford 1975, Quine & Chamley 1987). On the other hand many studies have failed to identify any clear and consistent relationship between the nature and extent of disability, the duration of caring and the adverse consequences experienced (Fengler & Goodrich 1979, Zarit *et al* 1980, Hawranik 1985, Parker 1985, George & Gwyther 1986, Fitting *et al* 1986, Winogron *et al* 1987, Eagles *et al* 1987, Motenko 1989).

There is similar confusion about the effects of caring on different groups. Some authors have considered women to be most at risk (Fitting *et al* 1986), others suggest spouses or resident carers irrespective of gender (Cantor 1983, George & Gwyther 1986), whilst still others identify young carers (Hirschfield & Krulick 1985). Furthermore factors considered to ameliorate carer distress differ widely and include the frequency of family visits (Zarit *et al* 1980, Hawranik 1985), carer perceived health and the nature of past carer/dependant relationships (Gilleard *et al* 1984) and the availability of information and appropriate service interventions (Silverstein 1984, Challis 1985).

Discrepant results such as these undoubtedly reflect in part the diversity of contexts for care. However, the search for common denominators which might help to explain stresses and strains in caring have also been hampered by

the small scale and focused nature of much previous work (Parker 1985). All this has been confounded by the failure to apply a consistent theoretical approach to the measurement of carer burden. This paper represents a modest attempt to begin bridging some of these important gaps.

Previous measures of carer burden

Early scaling instruments such as those produced by Zarit *et al* (1980) and Robinson (1983) are underpinned by the assumption that the discomforts caused by certain caring tasks or restrictions translate directly to feelings of burden or are stressful in themselves. Furthermore, such instruments often mix, and treat as synonymous, items concerning emotional reactions to caring with those merely seeking to ascertain if certain situations exist in the caring environment. In addition, the summative nature of these tools either assumes the equivalence of stimuli or masks the relative contribution that specific domains of burden make to the overall burden scores. In more recent work the use of factor analytic techniques has overcome some of these problems (Kosberg & Carl 1986) but the conceptual basis for such scales still assumes that because caring imposes certain restrictions, for example on the social life of carers, then this in itself will be stressful.

The notion of caregiving impact (on family relationships, social life, personal time and employment opportunities) and the degree of strain (on physical and emotional health and finances) as representing separate but related effects marked an important step forward (Cantor 1983). However the fact that impact and degree on strain were used only as dependent variables with no attempt to use impact as a predictor of strain or vice versa appears to limit the utility of these analyses.

Some of the conceptual and methodological confusion apparent in the measurement of carer burden was highlighted by Poulshock & Diemling (1984). In seeking to clarify the issues, they proposed that the term burden be restricted to subjective interpretations of events, preferring the term impact to denote the objective changes in carers' circumstances. A three-stage model was postulated in which burden acted as a mediating influence between levels of impairment in the dependant and the impact on the carer. Thus the model was seen to run in the causal direction

IMPAIRMENT → BURDEN → IMPACT

Following a series of multivariate analyses these authors contend that impairment in Activities in Daily Living (ADL), mediated via perceived burden, impacts on the carer's social life and that mental impairment, similarly mediated, affects family relationships. The value of this model lies in its

recognition of the importance of subjective factors in furthering our understanding of carers' problems. Nonetheless, there would appear to be a number of inherent difficulties of a conceptual order.

Firstly, the model is predicated on the assumption that perceived burden is inextricably linked with impairment and the extent of burden is thus confounded with impairment in the measurement process. The authors fall into the conceptual cul-de-sac noted by Zarit & Zarit (1982) of making the inferential leap between levels of impairment and the experience of burden.

Secondly, impact measures on social life and family relationships are treated as 'more or less objective' and no attempt is made to examine their perceived burden.

Furthermore, the impact measures used are unlikely to represent the ultimate consequences of caring and are more likely to be steps along the way to other adverse outcomes, which the empirical evidence already reviewed suggests are most probably manifested in some form of emotional disturbance.

Reconceptualizing carer burden

This necessarily perfunctory review of attempts to measure carer burden highlights the areas of conceptual inconsistency which are still apparent. The research on which the remainder of this paper is based places carer burden within a transactional model of stress and applies an empirical test for such an approach.

Seeking to explain one vague concept (burden) in terms of another (stress) might seem like replacing an enigma with a paradox. On the other hand, Clarke (1984a,b) suggests that there is an emerging consensus about the use of concepts of stress as a basis for professional interventions, with the recent literature leaning heavily on the idea of stress as being a transaction between an individual and his or her environment (Hatfield 1987, Spaniol & Jung 1987, Boss 1988, Chilman *et al* 1988). Such approaches owe much to the important work of Lazarus (Jacobson 1983) and despite the plethora of current models (Goosen & Bush 1979, Scott *et al* 1980, Jacobson 1983, Clarke 1984a,b, Spaniol & Jung 1987), each is underpinned by certain common assumptions. Within such a paradigm it is not the event itself which is important but the individuals' perception of the event. 'There's nothing either good or bad but thinking makes it so' (Shakespeare, *Hamlet*). This allows for the possibility of the same event being differentially stress-provoking for different individuals or for the same individual on separate occasions. An appraisal process determines reactions to potentially stressful events in the environment, with stress only resulting when there is

a cognitive imbalance between the perceived nature of the demand and the perceived capabilities of the individual concerned.

The foregoing is, of course, a much simplified description of transactional approaches to stress but highlights the central tenet of such models in that it is not the actual but the perceived capabilities and demands that are crucial. If burden is taken to represent the carer's perception of an event then the relevance of transactional definitions of stress to the investigation of burden becomes immediately apparent, as do the limitations of previous models of burden. The advantages of considering carer burden within a wider stress framework were recognised by Zarit *et al* (1986), but once again were limited by the failure to account for the differential stress effects of the same stimuli on varying individuals.

The utility of the transactional model in furthering our understanding of carer burden is tested below by the application of multivariate approaches to the analysis of empirical data. The model to be tested runs in the causal direction

ENVIRONMENT FACTORS → STRESS FACTORS → MALAISE

'Environment factors' are those to which a carer is exposed within the caring environment and include not only dependency variables, but also social life, financial implications of caring and the relationship between carer and dependant. 'Stress factors' are the carer's subjective appraisal of the degree of discomfort resulting from the environment factors and 'malaise' is the carer's score on a well known measure of stress.

METHOD

The detailed methodology for the study has been described elsewhere (Nolan & Grant 1989), but in order to place the present results in context will be briefly rehearsed again. A national sample survey of members of the Association of Carers (now Carers National Association) was undertaken using a postal questionnaire. The questionnaire comprised the usual details relating to biography, history of the caring relationship, dependency characteristics of the cared-for, together with open questions on the problems and satisfactions of caring. Also included was a previously validated measure of stress (the malaise inventory — Rutter *et al* 1970) together with a newly designed instrument, the Carer Perceived Problem Checklist (CPPC). The CPPC contained 30 potential problems carers might face which had been selected following a detailed review of the theoretical and empirical literature. It covered the domains

of social life, economic situation, relationship with dependant and the wider family, professional and family support, dependency factors and the carer's reactions to the demands of caregiving. The checklist comprised two sections which asked carers to consider if they experienced a particular stressor in their caring environment and, additionally, to indicate the degree of actual stress they perceived that stressor to provoke.

Questionnaires

Two thousand and fifty questionnaires were forwarded and 726 returned. Of these 554 were subjected to a series of multivariate analyses and 671 to a detailed content analysis. The results of the content analysis have already been described (Nolan & Grant 1989) and they provided a clear indication of the potential utility of the transactional approach to stress in furthering our understanding of carer burden. The results described below are from a complementary quantitative analysis using SPSSX and LISREL VI.

RESULTS

Data were subjected to a series of multivariate analyses including factor analysis and causal path analysis.

Factor analysis

These analyses were carried out using principal components analysis and varimax rotation with the normal default criteria. Three separate analyses were conducted, one on factors in the caring environment, one on the degree of stress that the environment factors were perceived to cause and one on the factor structure of the malaise inventory. From the first of these analyses, 11 factors emerged which have been termed environment factors. These indicate that the carer was exposed to, or experienced, certain combinations of stimuli in their caring environment. These factors, together with their factor loadings, are shown in Table 1. As can be seen, they form highly interpretable clusters of variables resulting in empirically meaningful factors.

Seven factors emerged from the second analysis and these are given in Table 2. These factors came from the 30 items on the CPPC and indicate that a carer perceives a stimulus to which they are exposed as stressful. It is apparent that these factors fittingly subdivide the construct system of perceived stress into similar partitions to those derived from the totally independent analysis of the caring environment.

Factor analysis on the malaise inventory was carried out using SPSSX and a confirmatory factor analysis using LISREL VI (Joreskog & Sorbom 1985). Both analyses failed to identify a single common factor. This is contrary to recent work (Bebbington & Quine 1987) but reflects earlier evidence which questioned the unidimensional nature of the malaise inventory (Hirst 1983). Based on the original description of the malaise inventory as an instrument containing both physical and psychological symptoms (Rutter *et al* 1970), and with supporting evidence from the present study (Grant *et al* 1989), a two-factor solution for the malaise inventory was introduced (Table 3). These two factors are highly interpretable and neatly divide the construct of malaise into what we have termed physical and psychological components. It was this two-factor solution that was used as the dependent variable in the causal path analyses.

Causal path analysis

Factor scores on these two sets of factors (Tables 1 and 2) were then used as explanatory variables of the two malaise sub-scales (Table 3) in a causal path analysis using LISREL VI. The LISREL model (Joreskog & Sorbom 1984, Saris & Stronkhorst 1984) allows estimation and testing of causal models using maximum likelihood estimation of covariance structure. Linear structural equation models represent causal theories with proportional and additive effects. The variables which the model should account for are called endogenous variables. The predetermined variables which are not explained by other variables in the theory are called exogenous. The effect on the i th endogenous variable from the j th endogenous variable is denoted by β_{ij} . The effect on the i th endogenous variable from the j th exogenous variable is denoted by γ_{ij} . If the data are standardized then β and γ represent path weights such that an increase of one standard deviation in the prior variable would cause an increase of $\beta(\gamma)$ standard deviations in the endogenous variable. Once a model has been formulated, the causal paths within the theory are specified, information about the covariances is obtained from the data, and LISREL estimates the causal effects and other parameters and tests the model against the data.

The type of model which was specified rests on few prior assumptions. It has few restrictions in that any prior abilities may affect any later ones. The aspects of the caring environment were taken as the exogenous variables, since those studies reviewed show carers to score highly on stress and malaise measures, and there can be little or no opportunity for stressed individuals to self-select as carers. These environment factors have then been allowed to

Table 1 Factor structures for caring environment

Factor	Factor loading	Factor	Factor loading
1 <i>Degree of physical help variable</i>		5 <i>Carer's reactions to caring</i>	
To dress	0.84	Carer can't relax/worried about caring	0.71*
To wash	0.78	Carer feels out of control	0.69*
To toilet	0.76	Carer experiences guilt	0.63*
To mobilize	0.72	Caring threatens emotional health	0.57*
To bathe	0.71	Caring threatens physical health	0.51*
With personal care	0.65*	Caring affects sleep	0.45*
To feed	0.63	Carer feels angry	0.40*
Dependant is immobile	0.51*	Carer feels physically tired	0.40*
With housework	0.38	Caring strains family relationships	0.38*
Carer feels physically tired	0.31*		
2 <i>Carer/dependant relationship</i>		6 <i>Restrictions on social life</i>	
Dependant is unappreciative	0.75*	Caring affects social life	0.69*
Dependant doesn't help carer	0.72*	Carer has no time for friends	0.67*
No meaningful relationship	0.61*	Carer has no private time	0.64*
Dependant is manipulative	0.60*	Carer has few holidays	0.62*
Dependant is too demanding	0.59*	Carer feels physically tired	0.43*
No satisfaction from caring	0.56*	Caring threatens emotional health	0.32*
Dependant's behaviour difficult	0.54*		
Dependant becomes agitated	0.45	7 <i>Financial consequences</i>	
Carer feels angry	0.44*	Carer experiences financial problems	0.73*
Dependant's behaviour upsetting	0.41	Caring lowers standard of living	0.70*
		Caring threatens physical health	0.42*
		Caring affects sleep	0.37*
3 <i>Incontinence</i>		8 <i>Lack of family support</i>	
Urinary incontinence at night	0.83	Family don't help much	0.83*
Urinary incontinence during day	0.83	Relatives don't visit often	0.81*
Dependant is incontinent	0.78*	Carer feels angry	0.34*
Faecal incontinence at night	0.75		
Faecal incontinence during day	0.74	9 <i>Lack of professional support</i>	
Help required to toilet	0.33	Professionals don't help much	0.79*
		Professionals don't understand carer's problems	0.78*
4 <i>Dependant's confused behaviour</i>		10 <i>Family relationships</i>	
Difficulty with normal conversation	0.78	Carer has no time for family	0.77*
Dependant is disorientated	0.77	Caring threatens family relationships	0.53*
Dependant's behaviour upsetting	0.68	Dependant is manipulative	0.33*
Dependant wanders	0.67		
Dependant becomes agitated/aggressive	0.69	11 <i>Other problems</i>	
Dependant's behaviour a problem	0.44*	Other problems	0.87**
Dependant is immobile	-0.31	Help needs with housework	0.39

*These variables are taken from column A of the CPPC and indicate that the carer is exposed to these problems in his/her caring environment

**A dichotomous variable indicating that the carer identified further problems to caring in the open questions

NB Minus sign indicates the more mobile the greater the problem

affect all of the endogenous variables (Both stresses specific to caring and general malaise factors. Thus gamma paths were allowed to run to all of the endogenous variables)

Furthermore, beta paths were allowed to run from the caring specific stressors to malaise factors. This type of

fully saturated model initially fitted is shown in Figure 1. The F factors, along with INT, a measure on a seven-point scale of the frequency of caring provision, are the exogenous variables. All possible causal paths (γ) between these and all the stress (S) and malaise (M) factors were

Table 2 Stress factors

Factor	Factor loading	Factor	Factor loading
1 Carer/dependant relationship variable		3 Physical demands of caring	
Dependant is unappreciative	0.68	Help required with personal care	0.62
Dependant's behaviour a problem	0.64	Carer feels physically tired	0.49
Dependant doesn't help carer	0.60	Dependant is immobile	0.46
Dependant is too demanding	0.58	Dependant is incontinent	0.46
Dependant is manipulative	0.57	Caring threatens physical health	0.45
No meaningful relationship	0.56	Caring affects sleep	0.41
No satisfaction from caring	0.47	Carer can't relax	0.35
Carer feels angry	0.37	4 Restrictions on social life	
Caring threatens family relationships	0.35	Carer has no time for friends	0.63
Caring threatens emotional health	0.34	Caring affects social life	0.62
Carer feels guilty	0.32	Carer has few holidays	0.45
Carer has no time for friends	0.32	Carer has no private time	0.36
2 Carer's reaction to caring		Caring threatens emotional health	0.35
Carer feels out of control	0.61	5 Lack of family support	
Carer can't relax	0.56	Family don't help much	0.80
Carer feels guilty	0.49	Relatives don't visit often	0.66
Caring threatens emotional health	0.46	6 Lack of professional support	
Carer has no private time	0.45	Professionals don't understand problems	0.95
Carer feels angry	0.39	Professionals don't help much	0.54
Caring threatens family relationships	0.37	7 Financial consequences	
Caring threatens physical health	0.36	Carer experiences financial problems	0.73
Caring affects sleep	0.33	Caring lowers standard of living	0.61

All variables are taken from column B of the CPPC and indicate that the carer was exposed to and found stressful certain aspects of caring

allowed, as were all possible paths (β) from the stress variables to the malaise factors. Covariation between the complete set of variables within each column was also permitted.

Model specification

The model specification entails that the beta and gamma weights on the causal paths reflect specific direct causal weights between the variables controlling for all indirect effects, spurious relationships and joint effects. On completion, the saturated model was 'tuned' in progressive stages guided by the *t*-values of the paths in the model and the modification indices of those omitted (LISREL computes modification indices for all paths which are not specified in the theoretical model being tested. Paths with high modification indices are those which would improve the fit of the model to the data if they were indeed specified in the original model). The final model had a goodness of fit index

of 0.981 and does not deviate significantly from the data on the chi-squared goodness of fit test. It should be emphasized that LISREL has been used in an exploratory fashion due to the numerous possible models that could be reasonably postulated for such a diverse data set. However the resultant model is both theoretically plausible and empirically relevant. It explains 47% of the variance in 'psychological malaise' (M1) and 20% of the variance in 'physical malaise' (M2).

For the sake of clarity and simplicity the resultant models are presented here in diagrammatic form. In these diagrams, significant paths are indicated by arrows, the widths of which are linearly related to the size of their effects. The model for 'psychological malaise' is given in Figure 2 and that for 'physical malaise' in Figure 3.

Inspection of the model for psychological malaise reveals a number of striking features. Firstly it is a powerful model accounting for 47% of the variance. However it is apparent that certain factors have no explanatory power and these

Table 3 Factor structure malaise inventory

Factor	Factor loading
<i>1 Psychological malaise variable</i>	
Does every little thing get on your nerves and wear you out	0.69
Are you easily upset and irritated	0.65
Are you constantly keyed up and jittery	0.62
Do you often feel miserable and depressed	0.62
Do you often get worried about things	0.54
Do people often annoy and irritate you	0.52
Do you have difficulty falling or staying asleep	0.49
Do you become scared for no good reason	0.49
Do you often get in a violent rage	0.48
Do you feel tired most of the time	0.46
Do you wake up unnecessarily early	0.40
Are you scared to be alone	0.38
Do you worry about your health	0.35
Is your appetite poor	0.34
Are you scared of going out or meeting people	0.33
<i>2 Physical malaise</i>	
Do you often suffer from an upset stomach	0.63
Do you suffer from indigestion	0.63
Do you have a twitching of head, shoulders or neck	0.50
Do you have bad pains in your eyes	0.44
Does your heart often race like mad	0.44
Do you often have bad headaches	0.44
Do you often have backache	0.41
Are you troubled with rheumatism or fibrositis	0.38
Do you worry about your health	0.37

NB For the sake of parsimony the wording of items in the above table does not correspond exactly to that in the malaise inventory as used in the present study. One variable 'Have you ever had a nervous breakdown' did not load on to either of the two factors

include the degree of physical care and assistance the dependant requires, levels of incontinence, the extent of the dependant's confused behaviour and the restrictions on the carer's social life. Furthermore, with the exception of factor 5, none of the environment factors exert any direct effect on malaise, but are all mediated via the perceived degree of stress that they are seen to cause. This is precisely what a transactional model of stress would predict.

From a close examination of the model it is clear that psychological malaise results from a complex interaction of factors. However, of those factors implicated four have a dominant role: the nature of carer/dependant relationships, the carer's response to the caring role, a lack of family support, and adverse financial consequences. Of these four factors it is the nature of the carer's response to their role that is most important. The factor loadings (S2, Table 2) give an indication of which variables are dominant. It appears that malaise is most likely to occur when the carer feels out of control, unable to relax because of worry about caring and experiences guilt about the situation. In circumstances such as these the carer perceives their emotional well-being

to be threatened. Malaise is heightened when the carer feels that the dependant does not appreciate their efforts and exhibits problem behaviour in terms of failing to help and being overly demanding and manipulative. Under these conditions carers find it difficult to sustain a meaningful relationship and consequently gain little satisfaction (S1, Table 2).

Those factors relating to lack of family support and the financial consequences of caring are largely self-explanatory, but are given support by the empirical literature which suggests that it is most often one family member who shoulders the main burden of care (Wicks & Henwood 1988).

In a multivariate analysis of this type, a case can always be argued that the results represent an artifact of the measurement process as much as they do the empirical reality. Fortunately, in the present study, powerful supporting evidence for the multivariate results is provided by a content analysis of 657 open-ended statements on the problems of caring and 546 such statements on the satisfactions of caring. The categories created during this phase of

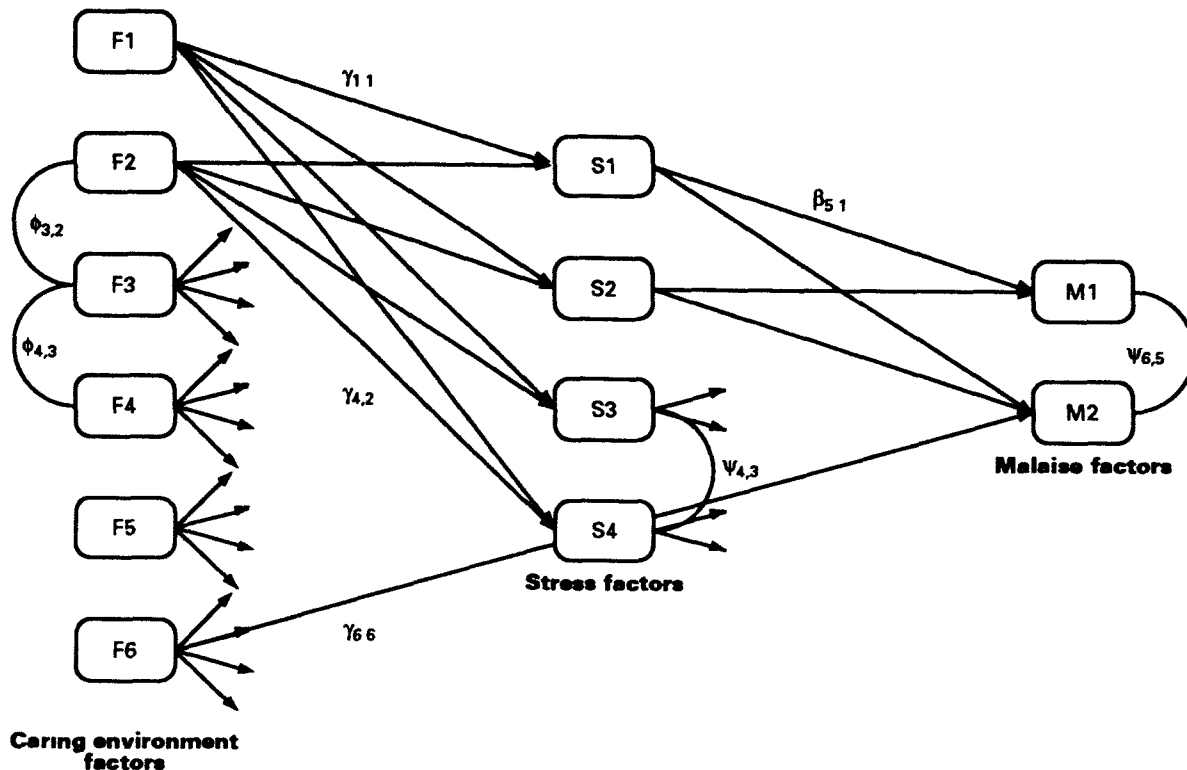


Figure 1

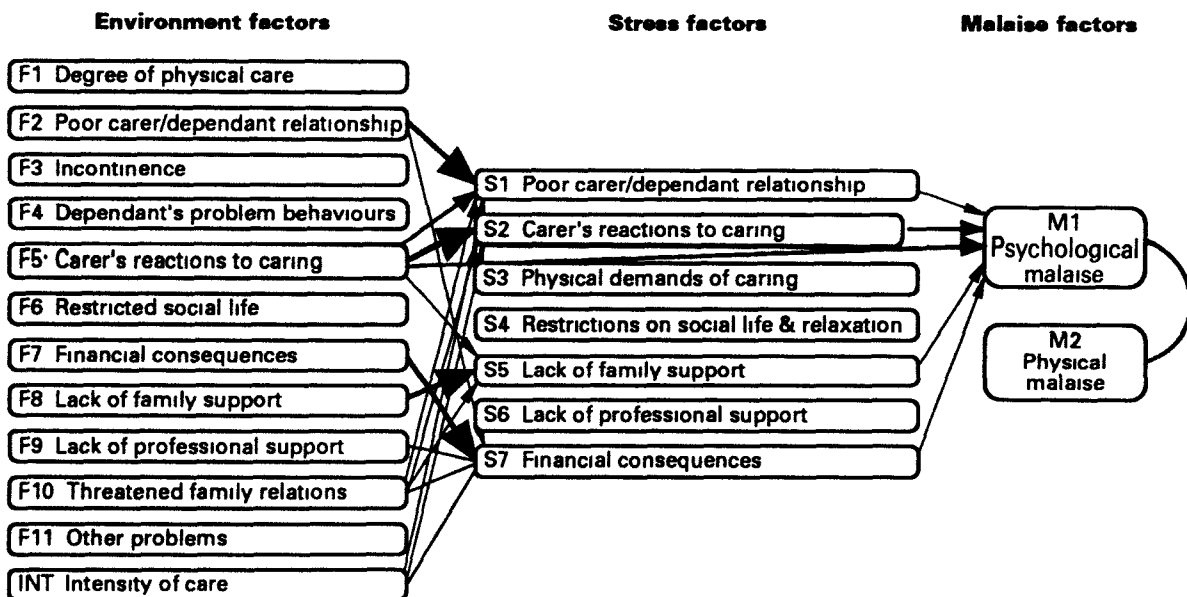


Figure 2

the analysis mirror almost exactly those produced from the factor analysis, yet the qualitative work was completed 3 months prior to the statistical analyses reported here

Model for physical malaise

Figure 3 shows the model for physical malaise and it will be seen that it is less powerful than that for psychological

malaise, explaining only 20% of the variance. Furthermore, in contrast to the model for psychological malaise, the explanatory variables, whilst being largely similar, exert their influence directly and not via their perceived stressfulness. It should also be noted that the dominant explanatory factor is the same as for psychological malaise but that the presence of variables relating to physical health, albeit at

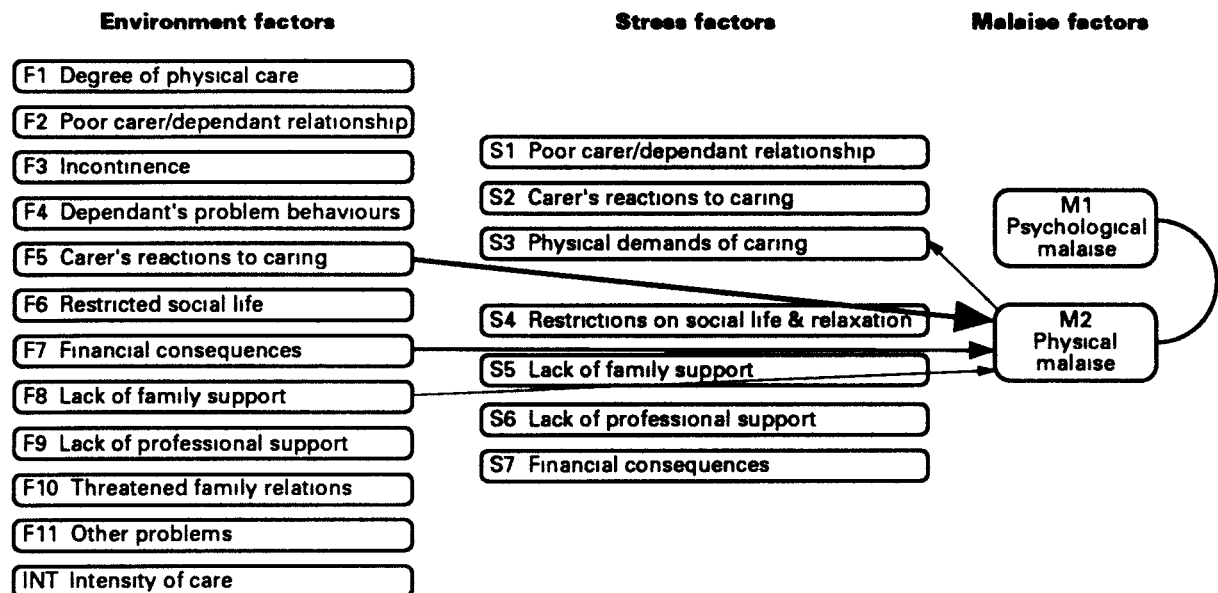


Figure 3

lower factor loadings, needs to be borne in mind. The occurrence of a high modification factor (36.7) back from physical malaise to the perceived stress caused by the physical demands of caring is of particular interest. This suggests that the physical demands of caring are not perceived as stressful until carers are themselves experiencing physical symptoms, indicating that whilst they are in good physical health carers do not find the physical demands of caring overly burdensome. The absence of any direct relationship between the physical demands of caring and physical malaise, but the direct influence of feelings of being out of control, guilt and so on (F5), highlights the central role of such reactions in furthering our understanding of both psychological and physical malaise. These results, together with those previously described from the qualitative analysis (Nolan & Grant 1989), have implications for practice issues relating to informal carers and it is to this area that attention is now turned.

DISCUSSION

In the introduction to this paper it was argued that, despite the burgeoning of research in the field of informal care, it is still not clear which aspects of caring are the most stressful and how such stress might best be alleviated. Consideration of previous attempts to operationalize and measure carer burden identifies similar deficits and it was suggested that carer burden might be better understood within a transactional model of stress. The empirical evidence from the present study using a triangulation of methods and data would appear to substantiate this suggestion. Taken

together these results highlight the importance of the carer's perceptions of the demands of the caring role, the extent to which they feel out of control of their situation and experience feelings of guilt and the central position of their relationship with their dependant. Carer malaise is also more likely when there is a lack of family support and adverse financial burdens imposed by caring *and* when the carer perceives these as stressful. These results can help to inform important practice decisions relating to the provision of services for carers and their dependants, which reinforce and extend those arguments previously posited (Nolan & Grant 1989). There it was suggested that service providers, and more particularly nurses, adopt an educative/supportive model in their interactions with carers and their dependants. Such an approach is underpinned by the acceptance of a transactional model of stress and the present analyses add to the validity of such assumptions.

Furthermore it seems clear that appropriate service provision needs to be informed by a detailed knowledge of carer/dependant relationships. Such knowledge is unlikely to be gained from a cursory assessment but requires a degree of trust between carer, dependant and the service provider. Such trust is best established where there is a sharing of caring tasks and regular contact between all parties. Given the high dependency and levels of disability with which many carers are faced, this places nurses in the unique position of providing care of an often very personal nature to the dependant, whilst also having the professional knowledge and expertise to give the carer advice, support and training.

This however requires a delicate balance in acquiring the trust of carer and dependant whilst giving due cognizance to both their needs (Hasselkus 1988, Thorne & Robinson 1988). A failure to achieve this balance can result in dependants feeling discredited (Charmaz 1983) and losing trust in the professionals' judgement (Thorne & Robinson 1988), with carers perceiving the quality of care as poor. Such considerations apply in both community (Hasselkus 1988) and institutional settings (Bowers 1988).

Whilst the notion of nurses making wider use of a stress/adaptation approach to their care is not new (Craig & Edwards 1983, Clarke 1984a,b), it is encouraging to see it resurfacing in conjunction with a nursing model (Watkins 1988). However, in order to make optimal use of such approaches in providing a service to carers and their dependants, there is a need to incorporate wider research evidence which extends our conceptualization of what constitutes caring (Bowers 1987) and provides a relevant theoretical basis for the enhanced understanding of carer/dependant relationships (Quershū 1986, Quershū & Walker 1986, Phillips & Rempusheski 1986).

Service providers

Balancing the requirements of carer and dependant with a relevant role for service providers has been further informed by the use of a family systems approach (Boss 1988, Chilman *et al* 1988). A most useful synthesis of such a paradigm within a typology of chronic illness and disability has been provided by Rolland (1988). This can act as a central reference point in taking the debate beyond the level of the medical model, whose utility is increasingly questioned (Allan & Hall 1988) and yet within which many practitioners remain trapped (Oliver 1988).

At the end of the day, if nursing is to offer an individual approach to the service we provide to dependency groups and their carers, then the issues raised above will need to be addressed. It is hoped that this paper will provide further stimulus for nurses and other professional groups to extend their knowledge and expertise in this increasingly important area.

References

- Allan J D & Hall B A (1988) Challenging the focus of technology — a critique of the medical model in a changing health care system *Advances in Nursing Science* **10**(3), 22–34
- Bebbington A & Quine L (1987) A comment on Hirst's 'Evaluating the Malaise Inventory' *Social Psychiatry* **22**, 5–7
- Bell R, Gibbons R & Pinchen I (1987) *Action Research with Informal Carers: Patterns and Processes in Carers' Lives Report on Phase 2*. Health Promotion Service, Cambridge
- Bonny S (1984) *Who Cares in Southwark*. Association of Carers, Rochester, Kent.
- Boss P (1988) *Family Stress Management*. Sage, California
- Bowers B J (1987) Intergenerational caregiving adult caregivers and their aging parents *Advances in Nursing Science* **9**(2), 20–31
- Bowers B J (1988) Family perceptions of care in a nursing home *The Gerontologist* **28**(3), 361–366
- Bowling A (1984) Caring for the elderly widowed — the burden on their supporters *British Journal of Social Work* **14**, 435–455
- Briggs A (1983) *Who Carers?* Association of Carers, Rochester, Kent
- Brody E M (1985) Parent care as a normative family stress *The Gerontologist* **21**, 19–29
- Cantor M H (1983) Strain among caregivers: A Study of experience in the United States *The Gerontologist* **23**(6), 597–604
- Challis D (1985) *Case Management and Consumer Choice — The Community Care Scheme*. Personal Social Services Unit, discussion paper 396. University of Kent, Canterbury
- Charmaz K (1983) Loss of self — A fundamental form of suffering in the chronically ill *Sociology of Health and Illness* **5**(2), 168–195
- Chilman C S, Nunnally E W & Cox F M (1988) *Chronic Illness and Disability Families in Trouble Series, Vol 2*. Sage, California
- Clarke, M (1984a) Stress and coping constructs for nursing *Journal of Advanced Nursing* **9**, 3–13
- Clarke M (1984b) The constructs of stress and coping as a rationale for nursing activities *Journal of Advanced Nursing* **9**, 267–275
- Craig H M & Edwards J E (1983) Adaptation in chronic illness: an eclectic model for nurses *Journal of Advanced Nursing* **5**, 475–484
- Eagles J M, Craig, A, Rawlinson F, Restall D B, Beattie J A G & Besson J A O (1987) The psychological well-being of supporters of the demented elderly *British Journal of Psychiatry* **150**, 293–298
- Equal Opportunities Commission (1982a) *Caring for the Elderly and Handicapped: Community Care Policies and Womens' Lives*. EOC, Manchester
- Equal Opportunities Commission (1982b) *What Cares for the Carers? Opportunities for those Caring for the Elderly and Handicapped*. EOC, Manchester
- Fengler A P & Goodrich N (1979) Wives of disabled men: the hidden patients *The Gerontologist* **19**(2), 175–183
- Fitting M, Rabin P, Lucas M J & Eastham J (1986) Caregivers for dementia patients: a comparison of husbands and wives *The Gerontologist* **26**(3), 248–252
- George L K & Gwyther L P (1986) Caregiver well-being: a multidimensional examination of family caregivers of demented adults *The Gerontologist* **26**(3), 253–259
- Gilleard C J, Belford M, Gilleard E, Whittick J E & Gledhill K (1984) Emotional distress amongst caregivers of the elderly mentally infirm *British Journal of Psychiatry* **145**, 172–177

- Goosen GM & Bush HA (1979) Adaptation — a feedback process *Advances in Nursing Science* 1(4), 91–100
- Grant G, Nolan MR & Ellis N (1989) *A Reappraisal of the Malaise Inventory* CSPRD working paper, University College of North Wales, Bangor
- Green H (1988) *Informal Carers General Household Survey 1985* Series GHS No 15, Supplement 16 Social Survey Division, OPCS HMSO London
- Gwyther LP & George LK (1986) Caregivers for dementia patients: complex determinants of well-being and burden *The Gerontologist* 26(3), 245–247
- Hasselkus BR (1988) Meaning in family caregiving perspectives on caregiver/professional relationship *The Gerontologist* 28(5), 686–691
- Hatfield AB (1987) Coping and adaptation, a conceptual framework for understanding families In *Families of the Mentally Ill Coping and Adaptation* (Hatfield AB & Lefley HP eds), Cassell Educational, London
- Hawranik P (1985) Caring for aging parents: divided allegiances *Journal of Geriatric Nursing* 11(10), 19–22
- Henwood M & Wicks M (1984) *The Forgotten Army Family Care and Elderly People* Briefing Paper Family Policies Study Centre, London
- Hirschfield MJ (1981) Families living and coping with the cognitively impaired In *Care of the Ageing* (Copp LA ed), Churchill Livingstone, Edinburgh
- Hirschfield MJ (1983) Homecare versus institutionalisation: family caregivers and senile brain disease *International Journal of Nursing Studies* 20(1), 23–32
- Hirschfield MJ & Krulick T (1985) Family caregiving to severely chronically ill children and the aged In *Longterm Care of the Elderly Recent Advances in Nursing* 15 (King K ed), Churchill Livingstone, Edinburgh
- Hirst M (1983) Evaluating the malaise inventory: an item analysis *Social Psychiatry* 18, 181–184
- Hooyman N, Gonyea J & Montgomery R (1985) The impact of in-home services termination on family caregivers *The Gerontologist* 24(2), 141–145
- Jacobson SF (1983) An overview of coping In *Nurses under Stress* (Jacobson SF & McGrath HM eds), Wiley, New York
- Joreskog KG & Sorbom D (1984) *LISREL VI User's Guide* University of Uppsala, Uppsala
- Joreskog KG & Sorbom D (1985) *LISREL VI Analysis of Linear Structural Relationships by Maximum Likelihood, Instrumental and Least Squares Method* University of Uppsala, Uppsala
- Kosberg JI & Carl RE (1986) The cost of care index: a case management tool for screening informal carers *The Gerontologist* 26(3), 273–278
- Motenko AK (1989) The frustrations, gratifications and well-being of dementia caregivers *The Gerontologist* 29(2), 166–172
- Nolan MR & Grant G (1989) Addressing the needs of informal carers: a neglected area of nursing practice *Journal of Advanced Nursing* 14(11), 950–961
- Oliver M (1988) Flexible services *Nursing Times* 84(14), 25–29
- Parker G (1985) *With Due Care and Attention A Review of Research on Informal Care* Occasional paper No 2 Family Policy Studies Centre, London
- Phillipson C (1988) *Planning for Community Care Facts and Fallacies in the Griffiths Report Working paper 1* Centre for Social Gerontology, Keele University
- Phillips LR & Rempusheski VF (1986) Caring for the frail elderly at home: toward a theoretical explanation of the dynamics of poor quality family caregiving *Advances in Nursing Science* 8(4), 62–84
- Poulshock WS & Deimling GT (1984) Families caring for elders in residence: issues in the measurement of burden *Journal of Gerontology* 39(2), 230–239
- Quine L & Charnley H (1987) The malaise inventory as a measure of stress in carers In *Evaluating Support to Informal Carers* (Twigg J ed), Conference papers York University, York.
- Qureshi H (1986) Responses to dependency: reciprocity, affect and power in family relationships In *Dependency and Interdependency in Old Age Theoretical Perspectives and Policy Alternatives* (Phillipson C, Bernard M & Strang R eds), Croom Helm London
- Qureshi H & Walker A (1986) Caring for elderly people: the family and the state In *Ageing and Social Policy a Critical Assessment* (Phillipson C & Walker A eds), Gower, Aldershot
- Robinson BC (1983) Validation of a caregiver strain index *Journal of Gerontology* 38(3), 344–348
- Rolland JS (1988) A conceptual model of chronic and life threatening illness and its impact on families In *Illness and Disability Families in Trouble Series Vol 2* (Chilman CS, Nunnally EW & Cox FM eds), Sage, Beverly Hills
- Rutter M, Graham P & Yule W (1970) *A Neuropsychiatric Study in Childhood* Heinemann, London
- Sandford J (1975) Tolerance of debility in elderly dependants by supporters at home *British Medical Journal* 3, 471–473
- Saris WE & Stronkhorst HL (1984) *Causal Modelling in Nonexperimental Research* Sociometric Research Foundation, Amsterdam
- Scott DW, Oberst MT & Dropkin MJ (1980) A stress-coping model *Advances in Nursing Science* 3(1), 9–23
- Silverstein NM (1984) Informing the elderly about public services: the relationship between sources of knowledge and service utilisation *The Gerontologist* 24(1), 37–40
- Spaniol L & Jung H (1987) Effective coping: a conceptual model In *Families of the Mentally Ill Coping and Adaptation* (Hatfield AB & Lefley HP eds), Cassell, London
- Thompson DM (1987) *Calling All Carers* Association of Carers, South Manchester Branch
- Thorne SE & Robinson CA (1988) Reciprocal trust in health-care relationships *Journal of Advanced Nursing* 13, 782–789
- Tomlin S (1989) *Abuse of Elderly People An Unnecessary and Preventable Problem* British Geriatrics Society, London
- Twigg J (1986) *Introduction Evaluating Support to Informal Carers* Conference papers, University of York, York
- Watkins M (1988) Lifting the burden *Geriatric Nursing and Home Care* 8(9), 18–20

- Wicks M & Henwood M (1988) The demographic and social circumstances of elderly people In *Mental Health Problems in Old Age* (Gearing B, Johnson M & Heller T eds), Wiley, Chichester
- Winogron IR, Fisk A A Kirsling R A & Keynes B (1987) The relationship between caregiver burden and morale to Alzheimer's disease patient functioning in a therapeutic setting *The Gerontologist* **27**(3), 336–339
- Worcester MI & Quayhagen MP (1983) Correlates of care-giving satisfaction prerequisites to elder home care *Research in Nursing and Health* **6**, 61–67
- Wright FD (1986) *Left to Care Alone* Gower, Aldershot
- Zarit SH, Reever KE & Bach-Peterson J (1980) Relatives of the impaired elderly correlates of feeling of burden *The Gerontologist* **29**(6), 649–655
- Zarit SH & Zarit JM (1982) Measuring Burden and Support in Families with Alzheimer's Disease Elders Paper presented at the 35th Annual Scientific Meeting of the Gerontological Society of America, Boston, Massachusetts
- Zarit SH, Todd P A & Zarit JM (1986) Subjective burden of husbands and wives as caregivers a longitudinal study *The Gerontologist* **26**(3), 260–266

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