Caregiving and the Stress Process: An Overview of Concepts and Their Measures

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It can hardly go unnoticed that research into caregiving has become a flourishing enterprise. Several reasons explain this striking growth of interest. One concerns the changing demographic landscape of contemporary societies: people live longer; the longer they live, the more at risk they are for chronic ailments that impair their ability to care for themselves; and, because of medical advances, impaired survivors survive for longer periods of time despite their health problems. It is also clear, painfully so to many, that as the need for care for the chronically impaired grows, so do its costs and the elusiveness of its quality. We know that most families are committed to caring for impaired relatives at home (Shanas, 1979; Brody, 1985). It is likely that because of the formidable barriers to suitable institutional care, however, many families continue to keep their relatives at home even after their resolve has been worn down.

Given that these kinds of changes have made informal family caregiving a typical experience, it is understandable that its economic, social, and psychological impacts would become areas of intense research concern. The research, of course, has been driven by several disciplinary perspectives and theoretical orientations. Probably none is more prominent in current research into caregiving than that concerned, either explicitly or implicitly, with stress and its mediation. Indeed, caregiving is potentially a fertile ground for persistent stress. A brief consideration of caregiving will help to reveal why this is so.

Caregiving and Stress

Informal caregiving simply refers to activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves. Whereas caring is the affective component of one's commitment to the welfare of another, caregiving is the behavioral expression of this commitment. Giving care to someone is an extension of caring about that person. Looked at this way, caring and caregiving are intrinsic to any close relationship; that is, they are present in all relationships where people attempt to protect or enhance each other's well-being. Caring and caregiving are the sine qua non of what Cooley (1915) described as primary relationships. Indeed, because caregiving is embedded in ordinary relationships, it is, strictly speaking, not accurate to treat it as though it were itself a role. Instead, caregiving refers to particular kinds of actions that are found in the context of established roles, such as wife-husband, child-parent.

Considering how quotidian caregiving is, it hardly seems the stuff out of which severe stress springs. Under some circumstances, however, caregiving is transformed from the ordinary exchange of assistance among people standing in close relationship to one another to an extraordinary and unequally distributed burden. The emergence of a serious and prolonged impairment, such as Alzheimer's disease, is such a circumstance. Where impairment leads to increasing dependency on others for the satisfaction of basic needs, a profound restructuring of the established relationship can occur. Caregiving, which previously might have been but one fleeting component of an encompassing relationship, can now come to be the dominant, overriding component. Under conditions of chronic and progressive impairment, therefore, caregiving may imperialistically expand to the point where it occupies virtually the entirety of the relationship.

As the capabilities of parties to the relationship...
become increasingly imbalanced, the reciprocities and give and take that had existed fade into the past. This is especially the case where the disability involves cognitive deterioration, as in Alzheimer’s disease and other dementias. Help, assistance, and affection become unidirectional, eventually going only from the caregiver to the recipient. We shall later spell out some of the specific ingredients of caregiving that can exert a stressful impact. Whatever these specific ingredients are, the sheer dramatic and involuntary transformation of a cherished relationship is itself a major source of stress (Pearlin, 1983). It is altogether understandable, then, that scholars who study caregiving would be interested in the stress that befalls the caregiver. There are caregivers, of course, who manage to find some inner enrichment and growth even as they contend with mounting burdens. Nevertheless, it is difficult to imagine many situations that equal — let alone surpass — the stressfulness of caregiving to relatives and friends with severe chronic impairments.

Although caregiving has acted as a magnet in attracting the interests of stress researchers, those drawn to it don’t necessarily view it through the same theoretical or methodological lens. The confusing diversity and the shortcomings found generally in psychosocial stress research certainly find their way into research that deals specifically with caregiving. Diversity and confusion are not necessarily to be abhorred; perhaps these are the unavoidable by-products of any field that has rapidly generated intense research activity. But these by-products have their costs, primarily in the sprouting of inconsistent or seemingly discontinuous knowledge. There have been recent calls to move caregiving research toward greater sophistication (Zarit, 1989; Romeis, 1989). And there have also been efforts to bring sound measurement closer to the many aspects of caregiving and its impact (Lawton et al., 1989). The aim of this paper is to join in these efforts.

Procedures

To implement our aim, we do two things. First, we lay out a conceptual scheme for the study of caregiver stress and, second, we present a number of the measures we have developed to assess the multiple components of the scheme. Because the utility of measures depends on how well they reflect the concepts they are intended to assess, the measures we introduce here were developed after our conceptual framework. This framework is a product both of many years of research into the stress process and of considerable exploratory research among spouses and adult children who care for relatives with Alzheimer’s disease. Much of our general understanding of the stress process usefully applies to the study of caregivers, and what we have learned from the study of caregivers has usefully informed our general understanding of the stress process.

The measures that are presented were constructed from our current multiwave study of 555 caregivers in the San Francisco Bay Area and Los Angeles, probably the largest such study undertaken to date. The caregivers were recruited primarily from the pool of people who contacted local Alzheimer’s Associations (ADRA) in the San Francisco Bay Area and in Los Angeles County. We attempted to contact everyone who was a self-described primary caregiver of a noninstitutionalized spouse or parent (or parent-in-law) with Alzheimer’s or a similar dementia. In a subsequent screening call, we verified that these criteria were met. In those instances in which the person was not the primary caregiver, we asked for the identification and location of the family member who was primarily responsible for caregiving. When the caregiving was shared, we chose the spouse whenever possible. Three interviews will be conducted over a 2-year period, providing an opportunity to chart changes brought on by the institutionalization and death of patients, as well as changes that occur within the household caregiving situation. Two interviews have been completed, but only the framework guiding the first is presented here.

In Table 1 the distributions of key characteristics of the sample are shown separately for spousal and adult children caregivers. It can be noted that the proportions who are husbands, wives, daughters, or sons are almost the same as in a national study of caregivers (Stone, Cafferata, & Sangl, 1987). The sample is tilted toward the middle class, as indicated by educational status. In this respect, too, it is similar to other caregiver studies. By no means can this sample be thought of as representative of all caregivers. Indeed, even if it were, we would not know it because the universe it would represent is unknown. What is important to recognize is that the distribution of characteristics is sufficiently broad to permit the analysis of their associations with other attributes of the caregivers.

The measures are presented as appendices rather than as part of the text; this better allows for their separate and detailed examination. Not all of the measures and scales used in our research are included in the appendices. Essentially, only newly created measures of key experiences or dispositions are included. Several others are described in the text but not appended. Although most of the measures presented in the appendices are based on the factor analyses of data gathered from the 555 participants, the construction of these measures began with the open-ended exploratory interviews. In these interviews, caregivers were asked about the problems they faced, the actions, feelings, and sentiments evoked by these problems, and their attempts to manage their difficulties. From the transcripts of the interviews, conceptual themes were identified and structured questions formed. These questions were then put through a series of pretests and revisions before being incorporated into the final scheduled interview. The manner in which the measures were developed as well as their psychometric properties provide us with an overall sense of confidence that they are serviceable and reliable indicators of our concepts.

A final introductory comment. The conceptual
framework we shall outline and the measures of its components are not presented as footsteps to be followed by others engaged in caregiver research. Fortunately, there is more than one way to think about the issues we address and more than one way to measure constructs. Our hope is to provoke critical thinking about issues that deserve attention and to bring choices into clearer awareness as future research is planned. In this way, perhaps, these materials will contribute to the coherence of a field of research that is somewhat fragmented and not as substantial as is warranted by the importance of its subject matter.

The Conceptual Components of Caregiver Stress

One will find that a number of the elements of caregiver stress in which we are interested are also to be found in the research of others. However, areas of overlapping interest are likely to have different conceptual underpinnings. Basically, we approach the study of caregiver stress from the perspective of what has come to be referred to as the stress process. The very notion of process forces attention on the relationships among the many conditions leading to personal stress and the ways these relationships develop and change over time. From this perspective, we are not interested in simply identifying conditions that might be associated with stress as much as in knowing how these conditions arise and how they come to be related to each other. Four domains make up this process, each comprising multiple components. The domains are: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress. As we describe each of these, the notion of a stress process in caregiving will become clearer. Figure 1 is presented as a graphic guide to our discussion.

The Background and Contexts of the Stress Process

Virtually everything we are interested in learning about caregiving and its consequences is potentially influenced by key characteristics of the caregiver. The effects of ascribed statuses, such as age, gender, and ethnicity, along with educational, occupational, and economic attainments are expected to be threaded throughout the entire stress process. These characteristics signify where people stand within stratified orders having unequal distributions of rewards, privileges, opportunities, and responsibilities. The kinds and intensities of stressors to which people are exposed, the personal and social resources available to deal with the stressors, and the ways stress is expressed are all subject to the effects of these statuses.

Links between social and economic characteristics of caregivers and other components of the stress process in which they are caught up are of utmost importance. They demonstrate that even seemingly random exigencies, such as the occurrence of Alzheimer's disease, can set in motion processes that to some extent are regulated and directed by the larger social orders of the society and the statuses of people within them. Caregivers may come to feel cut off from the larger society, but they are still very much influenced by its organization. Although these kinds of linkages have had some analytic attention in studies of caregiver stress, particularly with regard to gender (e.g., Zarit, Todd, & Zarit, 1986; Young & Kahana, 1989), they deserve much more. As we have

| Table 1. Distributions of Sample Characteristics of Alzheimer's Caregivers |
|-----------------|-----------------|-----------------|
| Variable        | Spousal caregivers | Children caregivers |
| City            |                  |                  |
| San Francisco   | 56%              | 52%              |
| Los Angeles     | 44               | 48               |
| Caregiver relationship |            |                  |
| Wife            | 58               |                  |
| Husband         | 42               |                  |
| Daughter        |                  | 76               |
| Son             |                  | 16               |
| Daughter-in-law |                  | 8                |
| Son-in-law      |                  |                  |
| Marital status  |                  |                  |
| Married         | 100              | 58               |
| Divorced/separated |              | 19               |
| Widowed         |                  | 8                |
| Never married   |                  | 15               |
| Living with AD person |            |                  |
| Yes             | 99               | 61               |
| No              | 1                | 39               |
| Race            |                  |                  |
| White           | 87               | 80               |
| Black           | 7                | 15               |
| Asian           | 2                | 3                |
| Hispanic        | 4                | 2                |
| Respondent education |              |                  |
| Less than high school | 18            | 6                |
| High school     | 29               | 25               |
| Some college    | 22               | 32               |
| College graduate| 14               | 18               |
| College +       | 17               | 19               |
| Employment status |              |                  |
| Employed        | 17               | 57               |
| Not employed    | 83               | 43               |
| Respondent age  |                  |                  |
| Less than 44    | 1                | 27               |
| 45-54           | 5                | 39               |
| 55-64           | 17               | 28               |
| 65-74           | 45               | 6                |
| 75-88           | 32               |                  |
| AD person age   |                  |                  |
| Less than 44    | 1                |                  |
| 45-54           | 2                |                  |
| 55-64           | 14               | 2                |
| 65-74           | 39               | 18               |
| 75-84           | 39               | 54               |
| 85-94           | 5                | 26               |
| Years caregiving|                  |                  |
| Less than 1     | 27               | 21               |
| 1-2             | 37               | 36               |
| 3-5             | 30               | 33               |
| 6 or more       | 6                | 10               |

<sup>a</sup>Spousal mean age = 70; child mean age = 51.
<sup>b</sup>Spousal mean age = 72; child mean age = 80.
Figure 1. A conceptual model of Alzheimer's caregivers' stress. The stress process is made up of four domains: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress.

observed elsewhere (Pearlin, 1989), information about people's statuses is too frequently gathered and then used only as statistical controls while looking at relationships among other conditions.

Aspects of the caregiving history are also taken into account. A number of items of information make up this history. Among them is the relationship of the caregiver to the patient, whether a husband or wife, son or daughter (or daughter-in-law). Information is also gathered about conflict and distance that might have existed in the past caregiver-patient relationship. Additional questions are asked about a range of physical health problems of the patient that could bear on caregiving demands. Finally, the length of time that the patient has required care is established. The duration of caregiving activities is, of course, a marker of the chronicity of the stressors that the caregiver experiences.

As can be seen in Figure 1, we also consider access to and use of resources and programs as important contextual elements of the stress process. We refer here to networks (including family) to which caregivers have attachments, the composition of the networks, and the nature and frequency of contacts with their members. It can be noted that the notion of network is different from that of social support. Network represents the totality of one's relationships, whereas support, which we treat as a mediator, pertains to the assistance one may derive from but a portion of the network (Pearlin, 1985). Although one cannot have social support without having a network, one may conceivably have a network without support.

Another type of resource is represented by community-based formal programs created to benefit patients, caregivers, or both. There are many programs that are designed to provide specialized services for patients or caregivers. However, the availability of such programs varies considerably from one community to another. They also vary in cost (and their affordability by caregivers), the availability of transportation to the programs, the hours of the day they function, and, of course, their proximity to the caregiver. Consequently, the actual use of programs by caregivers may be limited by a number of extraneous factors. To the extent that one can and does draw upon these kinds of resources, one can escape some of the vicissitudes and hardships of caregiving one might otherwise experience. From a structural perspective, many of these programs link the caregiver to the larger community. This linkage itself might help to reduce the isolation and alienation that many caregivers experience.

Primary and Secondary Stressors

We turn next to stressors, which are at the heart of the stress process in which caregiving may be embedded. These are the conditions, experiences, and activities that are problematic for people; that is, that threaten them, thwart their efforts, fatigue them, and defeat their dreams. Giving care to the seriously impaired can produce a variety of stressors. In earlier investigations of caregiving, especially those borrowing from the ground-breaking work of Zarit, Reeves, and Bach-Peterson (1980), multiple stressors were usually aggregated into unitary measures. Although these measures were discovered to be re-
lated to depression and other outcomes, their composite characters made it difficult to discern the particular stressors that contribute most to these outcomes. Although it is useful to know that global burden contributes to depression, eventually we need to know which specific burdens are most likely to result in depression and the conditions under which these burdens are most likely to be present. In this paper, we seek to identify and disaggregate some of the more salient stressors subsumed by the global notion of burden.

As seen in Figure 1, we divide stressors into those that are primary and secondary. We view primary stressors as driving the process that follows. By and large, they stem directly from the needs of the patient and the nature and magnitude of the care demanded by these needs. It is almost axiomatic that serious stressors, especially those that are chronic, generate other stressors. We conceive of the demands of caregiving as encompassing primary stressors that in turn lead to other problems and hardships, which we refer to as secondary. The labels of primary and secondary are not intended to suggest that one is more important than the other but only to point up that a configuration of interrelated stressors can and often does emerge as individuals are immersed in the long-term care of an impaired relative.

Primary stressors. — One indicator of a primary stressor is the cognitive status of the Alzheimer’s patient. The range and difficulty of caregiving activities and the ability of caregivers to manage their relationships with their impaired relatives grow out of the patient’s memory loss, communication deficits, and recognition failures. The evaluation of cognitive status, although made by the caregiver, is based on standard tests typically used in the clinic (Folstein, Folstein, & McHugh, 1975). The questions asking about cognitive status can be found in Appendix A. Questions about the validity of caregivers’ judgments of patients’ cognitive functioning may understandably arise. In this regard, it can be noted that about 75 of our participants care for relatives who are clients of the Northern California Alzheimer’s Disease Center, where independent clinical tests were administered to the patients. There is a strong correlation ($r = .65$) between the ratings caregivers give their relatives on our scale of cognitive functioning and the ratings of the same relatives made by clinical workers using the Mini-Mental Test. It would appear that caregivers are quite able to evaluate the cognitive abilities of their relatives with a high degree of accuracy.

A second and somewhat related indicator of a primary stressor entails the problematic behavior of the patient and the surveillance, control, and work such behaviors require on the part of the caregiver (Appendix B). The level of vigilance that must be maintained and the “damage control” that must be exercised to ensure that the patient harms neither himself nor others constitute, from all indications, a formidable stressor (Pruchno & Resch, 1989). Moreover, the special kind of attention required by such behavior serves as a constant and painful reminder of the changed persona of the patient.

A third indicator of a primary stressor is familiar to many studies of caregivers. It consists of the number of activities for which the impaired person is dependent on the caregiver and the extent of dependency for each activity. Activities for which this information is gathered are fairly standard (and, therefore, not appended) and include both those involved in satisfying daily needs (ADL) and instrumental logistical needs (IADL) (Katz et al., 1963; Lawton & Brody, 1969). It can be assumed that the more dependent impaired persons are, the greater is the sheer amount and difficulty of work caregivers must perform for them. Although it is entirely reasonable to treat daily dependencies as an indicator of hardship, research results do not show that the condition of the patient has a strong or consistent relationship to caregiver stress (e.g., George & Gwyther, 1986). It would seem that the magnitude of the workload by itself is not a potent stressor. We have learned, however, that when the efforts of the caregiver to satisfy daily and instrumental needs are met by resistance on the part of the recipient, then stress is more likely to result. Having to satisfy dependencies is by itself less difficult than having to do it with a recalcitrant relative. Consequently, we added to the assessment of daily dependencies a single question regarding the patient’s overall resistance to help.

Daily dependencies, problematic behaviors, and cognitive status are objective indicators of stressors in the sense that they are based on the health, behavior, and functional capabilities of the impaired relative. From this kind of information about patients, inferences can be drawn about the custodial care and attention the patient needs and the demands and hardships caregivers presumably encounter. It is also likely that the scope and difficulty of caregiving activities come to symbolize the changes that have overtaken the life and the self of the caregiver. Thus, these objective assessments of the patients’ behaviors and capabilities serve two purposes in our model: as indicators of the current demands of caregiving and as benchmarks of transformations that have already occurred and those that are expected.

Two additional indicators of primary stressors bypass the condition of the patient and inquire directly about hardships subjectively experienced by caregivers. One of these taps the overload or burnout felt by caregivers (Appendix C). The items constituting the measure bespeak not only the level of fatigue felt by caregivers but also the relentless and uncompromising nature of its source. The other we refer to as relational deprivation. As we have emphasized, Alzheimer’s disease and other dementias have a transforming effect on the patient and this, then, unavoidably restructures the caregiver-patient relationship, stripping it of its former reciprocities. As the impairment progresses, caregivers may come to feel increasingly separated from the parts of their lives that have been supported by or shared with their relatives.

The items making up the measure of relational
The care that person gives to the relative. The interaction and acknowledgment accorded the caregiver for the measures of conflicts involving the patient and by the other family members. Patient relatives of the disabled person, is rooted in disagreements, which, for the most part, involve dimensions of self-concept and kindred psychological states. Past research has indicated that under conditions of enduring hardships, self-concepts may be damaged (Pearlin et al., 1981), and when this happens, people are more likely to suffer symptoms of depression. Caregiving to chronically disabled relatives fits this scenario. The relentless and progressively expanding demands of caregiving, together with ensuing secondary role strains, are capable of diminishing positive elements of self; this, in turn, leaves people increasingly vulnerable to stress outcomes. In the conceptual framework portrayed by Figure 1, the intrapsychic strains represent the final but crucial step in an antecedent process.

Some of the self-concepts in which we are interested have traditionally been labeled in positive

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terms. These positive labels might appear discrepant with our references to stressful intrapsychic strains; however, what is regarded as strainful is not the presence of a positive self-concept but either its diminishment or barriers to its development. This is certainly the case with self-esteem and mastery, two elements of self-concept that have been closely studied in earlier stress research (Pearlin et al., 1981). Self-esteem, which simply refers to the regard in which one holds oneself, is measured by the Rosenberg (1965) scale. Mastery, or the control that individuals feel they are able to exercise over forces importantly affecting their lives, is measured by a scale previously developed by Pearlin (Pearlin & Schooler, 1978).

Self-esteem and mastery represent rather global and overarching elements of self. That is, they are constructs whose assessment is not tied to a particular context. In our current study of caregivers, we sought to expand our understanding of the place of the self in the stress process by including dimensions of self-concept that are anchored specifically in the caregiving situation and whose measurement reflects this context. There are four of these, one of which is role captivity (Appendix H). This is an intrapsychic strain that refers to being an unwilling, involuntary incumbent of a caregiver role. Essentially, the sense of being a captive exists when one wants to be and to do something other than that in which they feel compelled to engage. It is a concept that first emerged in a study of gender and depression (Pearlin, 1975) and was identified as an underlying theme in some of our exploratory interviews with caregivers. The loss of self is yet another theme that emerged from these exploratory interviews. To the extent that the identity and life of the caregiver has been closely bound to that of the patient, the caregiver may experience a loss of his or her own identity as the patient’s persona becomes fragmented and blurred. This loss may also be exacerbated when caregiving comes to exclude other activities and roles in which the caregiver previously found self-validation. Self-loss is measured by a simple two-item scale (Appendix I).

Two additional measures of intrapsychic strain, each phrased in positive terms, are competence and gain. Competence is measured by a four-item scale that essentially asks people to rate the adequacy of their performance as caregivers (see Appendix J). The measure of personal gain or enrichment (Appendix K) is testimony to the fact that many people manage to find some inner growth as they face the severe challenges of caregiving. Competence and gain were included partly out of interest in whether the enhancement of self is negatively related to stress outcomes, just as we knew the diminishment of self to be positively related to stress. They were also included to determine if the enhancement of some elements of self counterbalanced or compensated for the diminishment of others. This issue awaits further analysis.

These four measures of situational intrapsychic strain involve closely kindred constructs whose independence might be in question. In this regard, it is useful to note that the intercorrelations among the measures are not strikingly high. The strongest relationship (r = .35) is between role captivity and self-loss, and next in magnitude is the correlation between role competence and role gain (r = .33). The correlation between captivity and competence is -.17; between self-loss and competence it is -.13; and, finally, there is no correlation between self-loss and gain.

The differentiation in our conceptual model of primary and secondary stressors and the distinction between role and intrapsychic strains are heuristically important. This conceptualization is useful in revealing the dynamic character of caregiver stress, especially in multiwave studies extending over a broad time span. It treats stress not as stemming from a happening or from a circumscribed problem, but, rather, from the way caregivers’ lives become organized and the effects of this organization on their self-judgments. This perspective is particularly pertinent to caregiving, an activity that can result in far-reaching and enduring repercussions in the life of the caregiver and of every other family member in close contact with the situation. As we shall discuss, the distinction and specification of primary and secondary stressors also provides a more detailed picture of how and where the mediators may potentially intervene in the stress process.

Mediating Conditions

It is virtually always observed in stress research that people exposed to seemingly similar stressors are affected by them in dissimilar ways. This is certainly the case in studies of caregivers. It is the mediators that are usually called upon to provide the explanation for this outcome variability. Coping and social support are generally regarded as the two principal mediators. Analytic interest in these mediators in the study of caregivers is essentially the same as in stress research in general. That is, we seek to learn if differences in coping responses or in the use of social support can account for the fact that caregivers confronting equivalent life problems are unequally damaged by the problems. Why is it that some caregivers seem to fare better than others, though their life circumstances might not be easier? As we have argued elsewhere (Pearlin, 1990), the answer to this question probably cannot be answered solely by the mediators. Yet there is no doubt that they can have a major explanatory role.

Indeed, stress research may typically underestimate the power of the mediators. The usual mode of analysis is to determine if the strength of the relationship between a stressor and an outcome is reinforced or attenuated under different mediating conditions (see Wheaton, 1985, for detailed discussion). Buffering is assumed to take place when the cushioning effect of the mediator increases with the severity of the stressor. Buffering is a direct effect in the sense that its effects can be judged by looking directly at the outcome. However, the specification of primary and secondary stressors in Figure 1 suggests that there

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might also be indirect effects, which, if not observed, would lead to an underestimation of mediating effects. We refer specifically to the capacity of the mediators to limit the proliferation of secondary stressors. Thus, as suggested by the arrows in Figure 1, the mediators may serve both to lessen the intensity of stressors and to block their contagion at the junctures between the primary and secondary stressors. To the extent that these kinds of interventions occur, the mediators would indirectly be limiting deleterious outcomes. Obviously, these interventions need to be examined along with those that more directly reduce stressors and buffer the outcomes.

Coping. — Turning to the assessment of the mediators, we consider coping first. Coping represents behaviors and practices of individuals as they act on their own behalf. In keeping with our past research (Pearlin & Aneshensel, 1986), we conceive of coping in response to life problems as having three possible functions: management of the situation giving rise to stress; management of the meaning of the situation such that its threat is reduced; and management of the stress symptoms that result from the situation. We believe that it is strategically useful to measure these three functional aspects of coping separately and, more difficult, to measure each major life exigency with instruments specific to that exigency (Pearlin, Turner, & Semple, 1989). As others have also recognized (e.g., Quayhagen & Quayhagen, 1988), coping with caregiving cannot adequately be assessed with general-duty instruments or with instruments developed to measure how people cope with other life problems. Our measures meet these criteria: they assess the different functions of coping and are specific to the study of caregivers.

The items used to measure management of the situation (Appendix L) are not factored because there is no theoretical reason to suppose that the items are correlated in any structured order and, therefore, they will be analyzed as single items. The items that measure management of the meaning of the situation form three distinct factors (Appendix M). One involves the reduction of expectations (items A, B, & C), a second the use of positive comparisons (items D, E, & F), and the third a search for a larger sense of the illness (items G, H, & I). It can be seen that these subscales do not have robust reliability coefficients. Because of their instability, the measures assessing the management of meaning should be used with caution. Finally, we have a number of items that tap individuals’ efforts to lessen awareness of the situation or to decrease the symptoms of stress that result from it. These items, shown in Appendix N, are not scaled but will be analyzed separately. Note that the efficacy of coping cannot be judged solely by the manifest content of questions asking about coping, no matter how reasonable the content might appear to be. As we have described in detail elsewhere (Pearlin, 1990; Pearlin & Aneshensel, 1986; Pearlin & Schooler, 1978) the efficacy of coping can be evaluated only through the analysis of its mediating effects at various junctures of the stress process.

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Social support. — Our observations concerning the direct and indirect interventions are as applicable to social support as to coping. Thus, it should be determined if, in addition to its direct buffering effects, social support prevents or inhibits the development of secondary stressors. There is, of course, a sizeable literature on the role of social support in the stress process and the various ways to measure it (House & Kahn, 1985; Lin, Dean, & Ensel, 1986). We rely on assessments of two types of support that are central to the construct: instrumental and expressive support. The availability of instrumental support is measured by discrete items asking, for example, whether there is someone who assists the caregiver in the care of the relative or who helps with household chores. Expressive support is scaled (Appendix O), with its items tapping the perceived availability of a person who is caring, trustworthy, uplifting, and a confidant.

Outcomes

Social scientists are interested in the stress process because it helps to highlight the structural arrangements of the society and its institutional forces that affect people’s lives. The effects — or outcomes — that are usually observed in social research involve the well-being of people, their physical and mental health, and their ability to sustain themselves in their social roles. These are precisely the kinds of outcomes we have taken for study. On the mental health side, they include standard symptom measures of depression, anxiety, irascibility, and cognitive disruptions. These measures (which are not appended) are primarily drawn from the Hopkins Checklist (Lipman et al., 1969; Derogatis et al., 1971). We also inquire fairly extensively about caregivers’ physical health, limitations in their ability to engage in usual activities, and the occurrence of injuries. Still another pivotal outcome is the yielding of caregiver activities. This can be gradual or abrupt, and it may entail either the transfer of responsibilities to others or the institutional placement of the disabled relative. These kinds of changes will be observed over the multiple waves of interviewing.

The various outcomes should not necessarily be treated as interchangeable ways to assess the stressful impact of the antecedent process. It may be more fruitful to consider the different types and levels of outcomes as interrelated. Our own view is that elements of emotional distress are likely to surface first and, if they persist, they may be eventually inimical to physical well-being. In instances where there is a deterioration in both the mental and physical health of the caregiver, it can be assumed that a reduction or reluctant yielding of caregiving becomes more likely to occur. Whether disengagement from active caregiving helps to promote recovery from its negative emotional and physical effects remains to be seen. In any event, it is evident that these kinds of long-term relationships among outcomes are forged only under sustained, chronic conditions of stress.
Discussion

This is a very brief sketch of a complex process whose components each merit a much more detailed discussion than provided in this paper. However, brief, the paper is intended to convey some of the conceptual specification and elaboration needed to understand the web of conditions joined together as the lives of caregivers move forward over time. It also provides an array of newly created measures of the various concepts. Although the development of measures is time consuming and painstaking, it is frequently necessary if we are to have a close union between concepts and their measures.

We believe that it is useful to think of caregiver stress not as an event or as a unitary phenomenon. It is, instead, a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers’ health and behavior. The mix is not stable; a change in one of its components can result in the change of others. A great deal has been learned in previous research about these components of the stress process and how they are best measured and evaluated. Obviously, however, much remains to be learned of how they enter into and shape the directions of caregivers’ lives.

Certain caveats are in order pertaining to our conceptual model — or, for that matter, any model. The constructs that are included and the hypothesized relationships among them provide only general guidelines for research. The model should be regarded as an heuristic device rather than as a literal reflection of realities and the pathways that join them, many of which are still unclear. In the case of the conceptual framework described here, our past work provides a level of confidence about its utility. Yet we are just as confident that as studies of caregiver stress advance and provide opportunities for the empirical testing of the model, it will need to be further modified and extended. Most certainly, some of the relationships among constructs that we have treated here as being unidirectional will prove to be reciprocal. The model, consequently, should be regarded as something to be built upon rather than something to be followed or perpetuated. The result, we believe, will be a keener appreciation of informal caregiving, what it entails and what it costs.

References

APPENDICES

Note: The reliability (alpha) of each scale is parenthetically noted next to the name of the scale. Next to each item is the mean value of responses to the item.

A. Cognitive Status (alpha = .86)
Now, I'd like to ask you some questions about your (relative's) memory and the difficulty (he/she) may have doing some things. How difficult is it for your (relative) to:

A. Remember recent events (2.8)
B. Know what day of the week it is (3.0)
C. Remember (his/her) home address (2.4)
D. Remember words (2.0)
E. Understand simple instructions (2.2)
F. Find (his/her) way around the house (1.3)
G. Speak sentences (1.7)
H. Recognize people that (he/she) knows (1.5)

Response categories: (4) Can't do at all; (3) Very difficult; (2) Fairly difficult; (1) A little difficult; (0) Not at all difficult.

B. Problematic Behavior (alpha = .79)
In the past week, on how many days did you personally have to deal with the following behavior of your (relative)? On how many days did (she/he):

A. Keep you up at night (1.8)
B. Repeat questions/stories (2.6)
C. Try to dress the wrong way (2.4)
D. Have a bowel or bladder "accident" (1.9)
E. Hide belongings and forget about them (2.3)
F. Cry easily (1.6)
G. Act depressed or downhearted (2.1)
H. Cling to you or follow you around (2.4)
I. Become restless or agitated (2.6)
J. Become suspicious, or believe someone is going to harm (him/her) (1.8)
K. Threaten people (1.3)
L. Show sexual behavior or interests at wrong time/place (1.1)

Response categories: (4) 5 or more days; (3) 3–4 days; (2) 1–2 days; (1) No days.

C. Overload (alpha = .80)
Here are some statements about your energy level and the time it takes to do the things you have to do. How much does each statement describe you?

A. You are exhausted when you go to bed at night (2.6)
B. You have more things to do than you can handle (2.6)
C. You don't have time just for yourself (2.6)
D. You work hard as a caregiver but never seem to make any progress (2.4)

Response categories: (4) Completely; (3) Quite a bit; (2) Somewhat; (1) Not at all.

D. Relational Deprivation
Caregivers sometimes feel that they lose important things in life because of their relative's illness. To what extent do you feel that you personally have lost the following? How much have you lost:

Deprivation of Intimate Exchange: (alpha = .77)
A. Being able to confide in your (relative) (3.1)
B. The person that you used to know (3.3)
C. Having someone who really knew you well (2.6)

Deprivation of Goals and Activities: (alpha = .67)
D. The practical things (he/she) used to do for you (2.0)
E. A chance to do some of the things you planned (2.9)
F. Contact with other people (2.3)

Response categories: (4) Completely; (3) Quite a bit; (2) Somewhat; (1) Not at all.

E. Family Conflict (Scales created by Shirley J. Semple)
Issues of Seriousness/Safety of AD Patient (alpha = .80)
Family members don't always see eye to eye when it comes to their relative who is ill. How much disagreement have you had with anyone in your family concerning any of the following issues?

A. The seriousness of your (relative's) memory problem (1.67)
B. The need to watch out for your (relative's) safety (1.41)
C. What things your (relative) is able to do for (him/her) (1.46)
D. Whether your (relative) should be placed in a nursing home (1.49)

Attitudes and Actions Toward Patient (alpha = .86)
Family members may differ among themselves in the way they deal with a relative who is ill. Thinking of all your relatives, how much disagreement have you had with anyone in your family because of the following issues? How much disagreement have you had with anyone in your family because they:

E. Don't spend enough time with your (relative) (1.65)
F. Don't do their share in caring for your (relative) (1.61)
G. Don't show enough respect for your (relative) (1.37)
H. Lack patience with your (relative) (1.46)

Attitudes and Actions Toward Caregiver (alpha = .84)
I've just asked you how your relatives act toward your (relative). Now I'd like to ask how they act toward you, the caregiver. Again, thinking of all your relatives, how much disagreement have you had with anyone in your family because of the following issues? How much disagreement have you had with anyone in your family because they:

I. Don't visit or telephone you enough (1.39)
J. Don't give you enough help (1.48)
K. Don't show enough appreciation for your work as a caregiver (1.35)
L. Give you unwanted advice (1.49)

Response categories: (4) Quite a bit of disagreement; (3) Some disagreement; (2) Just a little disagreement; (1) No disagreement.

F. Job-Caregiving Conflict (alpha = .75)
From your own personal experience, how much do you agree or disagree with the following statements about your present work situation? In the last 2 months or so:

A. You have had less energy for your work (2.4)
B. You have missed too many days (1.8)
C. You've been dissatisfied with the quality of your work (2.0)
D. Whether your (relative) should be placed in a nursing home (2.6)
E. You worry about your (relative) while you're at work (2.0)

Response categories: (4) Strongly agree; (3) Agree; (2) Disagree; (1) Strongly disagree.
G. Economic Strains (To be assessed by separate items)
These questions ask about your household expenses and your standard of living. Think back over your financial situation as it was just before you began to take care of your (relative).
A. Compared to that time, how would you describe your total household income from all sources? (3.4)
B. Compared to that time, how would you describe your monthly expenses? (2.4)
Response categories: (5) Much less now; (4) Somewhat less now; (3) About the same; (2) Somewhat more now; (1) Much more now.
C. In general how do your family finances work out at the end of the month? (1.6)
Response categories: (3) Not enough to make ends meet; (2) Just enough to make ends meet; (1) Some money left over.

H. Role Captivity (alpha = .83)
Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you:
A. Wish you were free to lead a life of your own (2.5)
B. Feel trapped by your (relative’s) illness (2.6)
C. Wish you could just run away (1.9)
Response categories: (4) Very much; (3) Somewhat; (2) Just a little; (1) Not at all.

I. Loss of Self (alpha = .76)
Caregivers sometimes feel that they lose important things in life because of their relative’s illness. To what extent do you feel that you personally have lost the following? How much have you lost:
A. A sense of who you are (1.6)
B. An important part of yourself (2.0)
Response categories: (4) Completely; (3) Quite a bit; (2) Somewhat; (1) Not at all.

J. Caregiving Competence (Scale created by Marilyn M. Skaff) (alpha = .74)
Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you:
A. Believe that you’ve learned how to deal with a very difficult situation (3.3)
B. Feel that all in all, you’re a good caregiver (3.6)
Response categories: (4) Very much; (3) Somewhat; (2) Just a little; (1) Not at all.

Think now of all the things we’ve been talking about: the daily ups and downs that you face as a caregiver; the job you are doing; and the ways you deal with the difficulties. Putting all these things together, how (WORD) do you feel?
C. Competent (3.3)
D. Self-confident (3.3)
Response categories: (4) Very; (3) Fairly; (2) Just a little; (1) Not at all.

K. Personal Gain (alpha = .76)
Sometimes people can also learn things about themselves from taking care of a close relative. What about you? How much have you:
A. Become more aware of your inner strengths (3.3)
B. Become more self-confident (2.7)
C. Grown as a person (2.9)
D. Learned to do things you didn’t do before (3.1)
Response categories: (4) Very much; (3) Somewhat; (2) Just a little; (1) Not at all.

L. Management of Situation (To be assessed by separate items)
Here are some things that people do to make caregiving easier for themselves. How often do you:
A. Try to be firm in directing your (relative’s) behavior (2.9)
B. Do the things you really have to do and let the other things slide (2.9)
C. Try to find ways to keep your (relative) busy (2.5)
D. Try to learn as much as you can about the illness (e.g., read books, talk to doctors, go to lectures) (3.2)
Response categories: (4) Very often; (3) Fairly often; (2) Once in a while; (1) Never.

Have you done anything to try to prevent your (relative) from having accidents or from wandering? If so, could you give me one or two examples of something you’ve done?

M. Management of Meaning
Here are ways that some people think about caregiving, and about their relative with memory problems. How often do you think in these ways? How often do you:
Reduction of Expectations (alpha = .48)
A. Try to accept your (relative) as (he/she) is, not as you wish (he/she) could be (3.4)
B. Try to think about the present rather than the future (3.3)
C. Try to keep your sense of humor (3.5)
Making Positive Comparisons (alpha = .63)
D. Remind yourself that others are worse off (3.2)
E. Try to think about the good times you had in the past (2.9)
F. Look for the things that you always liked and admired in your (relative) (2.9)

Construction of Larger Sense of Illness (alpha = .49)
G. Try to make sense of the illness (3.3)
H. Pray for strength to keep going (3.2)
I. Remind yourself that this is something to expect as people get older (2.3)
Response categories: (4) Very often; (3) Fairly often; (2) Once in a while; (1) Never.

N. Management of Distress (To be assessed by separate items)
Here are things that some people do when they are under stress from caregiving. How often do you do them?
A. Spend time alone (2.3)
B. Eat (2.0)
C. Smoke (1.4)
D. Get some exercise (2.3)
E. Watch TV (2.6)
F. Read (2.6)
G. Take some medication to calm yourself (1.3)
H. Drink some alcohol (1.4)
Response categories: (4) Very often; (3) Fairly often; (2) Once in a while; (1) Never.
O. Expressive Support (alpha = .87)
Let's turn now to the help and support you get from your friends and relatives. Thinking about your friends and family, other than your (relative), please indicate the extent to which you agree or disagree with the following statements.
A. There is really no one who understands what you are going through (Reversed) (2.8)
B. The people close to you let you know that they care about you (3.4)
C. You have a friend or relative in whose opinions you have confidence (3.4)
D. You have someone who you feel you can trust (3.6)
E. You have people around you who help you to keep your spirits up (3.3)
F. There are people in your life who make you feel good about yourself (3.4)
G. You have at least one friend or relative you can really confide in (3.5)
H. You have at least one friend or relative you want to be with when you are feeling down or discouraged (3.2)
Response categories: (4) Strongly agree; (3) Agree; (2) Disagree; (1) Strongly disagree.