

Caregiving Burden

Making the Concept Scientifically Useful and Policy Relevant

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This article critically examines the burden concept, its lack of clear definition, the inconsistency between its conceptualization and operationalization, its inappropriate use within the stress paradigm, and its marginal policy relevance. A needs-based conceptualization of burden is presented in which burden is defined in terms of frustration of basic needs arising from five characteristics of family care for frail elderly people: awareness of degeneration, unpredictability, time constraints, the caregiver-receiver relationship, and lack of choice. These contributors to burden are called crises of decline to contrast with the experiences normally encountered through child care. The model has received empirical support and represents a reconceptualization that not only accommodates the increasingly popular stress paradigm but also provides a bridge between research that focuses on burden as an individualistic phenomenon and research that links dominant caregiving practices with social injustice.

Burden has been a key concept in family caregiving research over the past decade. According to George and Gwyther (1986), caregiver burden is “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults” (p. 253). Sometimes the problems have been identified through the reports and the experiences of caregivers. At other times, they reflect the expectations of researchers. Ory et al.’s (1985) definition reflects the less experiential perspective: “Burden may be defined as the impact of the changes in cognition and behavior of the Alzheimer patient on the family, and the patient’s subsequent

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RESEARCH ON AGING, Vol. 14 No. 1, March 1992 3-27
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need for care and supervision” (p. 631). Thus, the term has covered everything from the debilities of the carereceiver and the feelings of the caregiver to the effects that caregiving has on the family from either a subjective or objective perspective.

As interest turned to understanding the process by which caregivers became burdened, the breadth of the burden concept has become a problem. Burden was multidimensional (Deimling and Bass 1986, Montgomery, Gonyea, and Hooyman 1985; Poulshock and Deimling 1984), and researchers wanted to pull the bits apart to understand the ways in which they were interconnected (George and Gwyther 1986; Haley, Brown, and Levine 1987; Ory et al. 1985; Stephens and Zarit 1989). Not surprisingly, a smorgasbord of possibilities has presented itself in recent years for defining and analyzing burden. At the time of her review, Horowitz (1985) noted consistency in findings despite variations in the definition and measurement of burden. This is no longer the case. Problems are emerging which limit scientific understanding and undermine policy initiatives to provide assistance to those giving care.

The usefulness of the burden concept has been questioned on a number of fronts. The diversity of definitions of burden (Morris, Morris, and Britton 1988; Platt 1985; Poulshock and Deimling 1984; Raveis, Siegel, and Sudit 1990), the scientific softness and fuzziness of the term (George and Gwyther 1985; Moritz, Kasl, and Berkman 1989; Schulz 1990), and its poorly articulated relevance to public policy (Abel 1990; Callahan 1989) all contribute to undermining the value of the concept. This article addresses these issues and argues for a theoretical framework, consistent with the widely supported stress paradigm, which provides a well-bounded definition of burden and articulates explicitly the relevance of burden to public policy.

Narrowing the Burden Concept Theoretically

Two major theoretical efforts to define the burden concept more precisely have been widely acknowledged in the caregiving literature. Hoenig and Hamilton (1966) distinguished objective from subjective burden, a distinction that was to be taken up in later years by Thompson and Doll (1982), Montgomery et al., (1985), and Platt (1985). Objec-

tive burden referred to the events and activities associated with negative caregiving experience. Subjective burden referred to feelings aroused in caregivers as they fulfilled their caregiving functions. To clarify the distinction, Platt (1985) pointed out that objective burden involves "disruption to family/household life that is potentially verifiable and observable" (p. 386); as such, objective burden differs from subjective burden, which depends entirely on caregivers sharing their "personal feelings" (p. 386).

The distinction between objective and subjective burden proved useful in that the correlation between the two types was shown to be comparatively low (Hoenig and Hamilton 1966; Montgomery et al. 1985). Burden was multidimensional, and either specification of components or restriction of the definition was essential if the concept was to have scientific validity and policy relevance. Poulshock and Deimling (1984) made a major contribution to resolving these difficulties by proposing a narrower definition of burden. Burden, they argued, should be distinguished from both the impairment of the carereceiver and the impact of caregiving on family members. Burden should refer to caregivers' distress arising from dealing with the carereceivers' physical dependence and mental incapacity. The separate concept of impairment could then be reserved for the carereceiver's inability to perform activities of daily living, cognitive incapacity, or difficult and disruptive behavior patterns. The effects of caregiving on family, social life, work, and employment was to be segregated into the domain of impact.

Poulshock and Deimling's (1984) work recognized burden as a subjective phenomenon. What was difficult for one caregiver need not be difficult for another: Burden lay in the experiences of the caregivers. Furthermore, this conceptualization added clarity to the confusion surrounding the meaning of burden. Yet conceptual difficulties did not resolve themselves in the literature. Researchers acknowledged Poulshock and Deimling's contribution but were hesitant to dissociate burden from impact (Miller, McFall, and Montgomery 1991; Novak and Guest 1989a). This dilemma is not surprising. The Poulshock and Deimling model does not take into account feelings about impact, and the literature suggests that distress arising from caregiving impact (e.g. role conflict) is just as central to burden as distress arising from the carereceiver's behavior (Cantor 1980; Dunkle

1985; Horowitz 1978). It is difficult to justify why distress over time constraints or family disharmony would not constitute burden while distress over an elderly person's memory loss would.

To accommodate this omission, Poulshock and Deimling's (1984) concept of burden can be extended to cover both distress in providing care and distress over the effects of caregiving on one's life. Such a compromise, however, sacrifices the clarity of the Poulshock and Deimling model, in that it demands distinguishing objective and subjective impact. While this is conceptually feasible, it is empirically problematic. Observing role conflict and reporting distress over role conflict are, in theory, two different things. In practice, an external observer wishing to infer role conflict from a caregiver's behavior is going to find it difficult not to be influenced by the meaning that the caregiver attaches to the events.

In spite of losses in conceptual clarity, most researchers appear comfortable with using burden to refer to both personal reactions to caregiving and the effects of caregiving. Although some studies have reported success in separating distress and impact measures (Cantor 1983; Greene, Smith, Gardiner, and Timbury 1982), most published data have given rise to doubts about their empirical separability. In Poulshock and Deimling's (1984) study, the burden subscales correlated as highly with the impact subscales as they did with each other, a finding that is not consistent with a model of burden and impact as cohesive but distinct concepts. Furthermore, a major study of the factorial structure of caregiving appraisal (Lawton, Kleban, Moss, Rovine, and Glicksman 1989) was unable to clearly and consistently differentiate subjective burden from impact. The most widely used unidimensional burden scales also have incorporated both feelings about giving care and about the effects on the caregiver's life. The majority of the 29 items in Zarit, Reever, and Bach-Peterson's (1980) Burden Scale commence with the phrase "I feel" and are concerned with the relationship between the caregiver and carereceiver. Also included, however, are feelings about the impact of caring in areas such as finance, social life, and physical and mental health. Similarly, Robinson's (1983) 13-item Caregiver Strain Questionnaire deals not only with reactions to impairment (e.g., upsetting to see changes), but also with impact from an objective (e.g., changing personal plans) and subjective perspective (e.g., experiencing financial strain). A similar

scale has been used by Gilleard, Gilleard, Gledhill, and Whittick (1984). Again 13 items were chosen to cover emotional and physical strain, household disruption, and reactions to behavior problems. Kosberg and Cairl's (1986) 20-item Cost of Care Index incorporates feelings about providing care and the effects that caregiving has on the caregiver and his/her family. Novak and Guest's (1989a) multidimensional measure of caregiver burden also fails to distinguish task requirements and impacts from affective responses. A recently published study by Vitaliano, Russo, Young, Becker, and Maiuro (1991) purports to assess objective burden and subjective burden independently. Their definition of objective burden, however, differs from the usual conceptualization. Objective burden refers to experiences that inevitably have a subjective component: for example, being upset that I cannot communicate with my spouse, feeling so alone — as if I have the world on my shoulders. Vitaliano et al. define subjective burden as the degree of distress caregivers associate with the experiences. Although the authors have measured the presence of experiences and the distress associated with these experiences separately, the conceptual distinction between them is not clear.

The core of agreement in usage of the burden concept concerns caregiving distress and covers expressions of "worry, anxiety, frustration, depression, fatigue, poor health, guilt and resentment" (Lawton, Kleban, et al. 1989) which may arise in response to the carereceiver's impairment, the giving of care, or the consequences of care. The problems that result are three-fold. The core domain remains enormous, posing serious problems for representative and comprehensive measurement before any issues of dimensionality need be debated. Second, the concept is clumsy for use in a stress paradigm that places great importance on the precise definition of the components of the stress process. Third, burden, defined in terms of feelings toward impairment and impact, has poor policy relevance and can have adverse effects on the very population that most researchers would prefer to assist.

FROM A CONCEPTUAL PERSPECTIVE

The scientific difficulties associated with the present breadth and vagueness of the conceptualization of burden can be illustrated by

focusing on one particular relationship that is crucial to understanding caregiving stress, as well as to implementing therapeutic interventions and directing policy: the extent to which carereceiver impairment and the workload of the caregiver affect burden. Schulz et al.'s (with Tompkins, Wood, and Decker 1987; with Tompkins and Rau 1988) work suggests that there is no simple answer to the conflicting results that have emerged on this question. One of the factors clouding the issue, however, could have been avoided by a more circumscribed definition of burden.

A number of studies have reported little relationship between the demands of caregiving and burden (Fengler and Goodrich 1979; Gilhooly 1984; Jenkins Parham, and Jenkins 1985; Kinney and Stephens 1989a; Moritz et al. 1989; Pagel, Becker, and Coppel 1985; Zarit et al. (1980). George and Gwyther (1986) concluded that there was little relationship between caregiving demands and well-being, but report an inconsistent pattern of results. Others report significant relationships (Deimling and Bass 1986; Morycz 1985; Pearson, Verma, and Nelle 1988; Schulz 1990; Stoller and Pugliesi 1989). Understanding these conflicting findings is greatly hampered, not so much by the use of different measures, but by confusion in how one defines the burden domain. Where burden has been successfully related to the carereceiver's impairment (Deimling and Bass 1986; Pearson et al. 1988), the hours of help provided (Stoller and Pugliesi 1989), and the number of tasks performed for the carereceiver (Morycz 1985), the burden measures give strong representation to items assessing impact on life-style. In contrast, burden measures used in studies that report no relationship between workload and burden tend to favor items tapping emotional well-being. Furthermore, where functional limitations and assistance provided have been related specifically to impact, consistent positive relationships have emerged (Cantor 1983; Greene et al. 1982; Montgomery et al. 1985; Poulshock and Deimling 1984). The need for greater assistance from the caregiver leads to restrictions in the caregiver's social life, family life, leisure activities, and work. Thus, the nature of the relationship between caregiving demands and burden depends, in part, on the balance of impact and distress items in the burden measure. The fuzzy boundaries between objective and subjective impact and the intuitively appealing linkage of feelings

about impairment and feelings about impact limit the usefulness of burden as a scientific construct.

FROM AN EMPIRICAL PERSPECTIVE

Increasingly, the stress paradigm has been applied to the caregiving situation (Haley, Levine, Brown, and Partolucci 1987; Kinney and Stephens 1989b; Schulz et al. 1987; Stephens and Zarit 1989). This development has brought with it greater opportunity to understand how burden comes about and the circumstances under which burden can be minimized (Pearlin, Mullan, Semple, and Skaff 1990; Stephens and Zarit 1989). One of the major controversies in the stress literature has concerned the overlapping of measures (Dohrenwend, Dohrenwend, Dodson, and Shrout 1984; Lazarus, DeLongis, Folkman, and Gruen 1985). Dohrenwend et al. have argued for a clear distinction between objective stressors on the one hand and subjective stress reactions on the other. They have been critical of the subjective appraisals that Lazarus and Folkman (1984) introduced into the stress process because of possible measurement contamination between the independent and dependent variables. The problem of measures of independent and dependent variables overlapping in their content, and therefore necessarily correlating, is likely to occur when the burden concept is defined broadly. In the burden literature the problem has been raised by George and Gwyther (1986), Kinney and Stephens (1989b), and Vitaliano, Young, and Russo (1991).

The effect of an imprecise definition of burden when the stress paradigm is being used can be illustrated once again by studies that have reported on the workload-burden link. From a stress perspective, the things the caregiver does for the carereceiver constitute environmental stressors, which caregivers will interpret in certain ways and will adapt to with differing degrees of success (Lazarus and Folkman 1984). Ensuring that stressor measures are distinct from appraisal measures, which, in turn, are distinct from adaptational measures, is not always straightforward. The impairment of the carereceiver is often translated into workload variables, and together they can be conceptualized as environmental stressors. Upset about caregiving tasks and demands constitutes the caregiver's appraisal or reaction to the environmental stressors. Strain in the household might constitute

the adaptation measure. From a stress perspective, the relationship among these measures is the focus of attention. If the items used to assess appraisal and strain, however, are tied to the presence of specific types of impairment, it is inevitable that relationships between the three concepts will emerge. The measures are not independent in that responses on one measure are logically constrained by responses on another.

In Kinney and Stephen's (1989b) study of the stress process, three types of variables were measured: environmental stressors, appraisals, and adaptation. The stressors were measured through the frequency of occurrence of 110 events associated with caregiving. Appraisal was assessed by asking caregivers to indicate how much of a hassle and how much of an uplift the experienced events were. Poulshock and Deimling's (1984) Social Impact Scale was one of the two adaptation measures used. As Kinney and Stephens point out, the measures of hassles and impact are not distinct and may be tapping the same construct. The hassle of a carereceiver "not cooperating" and "asking repetitive questions" is not dissimilar from the impact items, "relationship with elder is strained" and "elder makes more requests than necessary." Furthermore, Kinney and Stephens report that caregivers to the more physically impaired experienced not only more activities of daily living (ADL) hassles but more uplifts. Whether or not any significance should be attached to these findings is difficult because answering the question on either hassle or uplift is dependent on the elder having that particular impairment. Few impairments means that the caregiver is likely to have fewer hassles and fewer uplifts.

In their classic study advocating independent measures, Poulshock and Deimling (1984) experienced similar problems of confounding. The impairment measure (an environmental stressor) involved the elder in being withdrawn and unresponsive, disrupting meals, being unpleasant, and doing harmful things to self and others. The highly evaluative component in these items leads one to expect a positive correlation with burden when the latter is assessed as the extent to which each particular impairment upset the caregiver.

A more recent study by Miller et al. (1991) illustrates the persistence and pervasiveness of the problem in caregiving research. Miller et al. found that impairment and task involvement influenced personal and interpersonal burden. Close scrutiny of the items used to measure the

burden concepts, however, shows some to be relevant to the concepts of task involvement and impairment: for example, elder needs constant attention, elder forgetting things, and elder lapsing into senility. Measures that are not independent of each other introduce an inflation or suppression effect into the correlation coefficient which often is not recognized when inferences are being drawn from the data.

FROM A POLICY PERSPECTIVE

As noted earlier, at the core of definitions of burden is the notion of distress. Distress, in itself, is not a persuasive argument for resource allocation to groups by policymakers. Clearly, as a criterion for government support, it is open to abuse. Every group wanting support can express their discontent in this way. Distress is an individualistic response that may or may not arise out of need. Forsaking a holiday and recreational activities may cause enormous upset, but policymakers are unlikely to regard caregivers as a seriously disadvantaged group on the basis of such sacrifices.

The above argument assumes that clients will use exaggeration and melodrama to gain resources. It is important to note that caregivers' feelings of loyalty and dedication often lead them to downplay their own distress. Becker and Morrissey (1988) observed this phenomenon when interviewing caregivers:

Despite patently depressed faces and vocal tone, our Alzheimer caregiver subjects would initially admit to only slight occasional . . . feelings of depression. But as the interview progressed with a systematic inquiry about depression-related symptoms, these same subjects would sometimes experience a very substantial welling of dysphoric affect denoting at least the presence of severe depressive emotion if not of depressive mood. (p. 304)

Regardless of whether emotions are overplayed or underplayed in the caregiving context, burden, as distress, is not useful directly in guiding social policy.

Nevertheless, burden has indirect policy relevance because of its association with the family's decision to relinquish the caregiving role and seek institutional forms of care (Colerick and George 1986; Morycz 1985; Pruchno, Kleban, Michaels, and Dempsey 1990). Gov-

ernments in the Western world have enjoyed cost savings generated by the unpaid work force of family caregivers. These people, primarily women, have been seen as a resource that could be further used if an investment were made in programs to help with home care. The assumption has been that such programs would reduce the burden on caregivers, thereby maintaining or increasing their commitment to care and postponing or avoiding the need for institutional care.

Data to support this line of argument have not been forthcoming. The interventions geared specifically to caregivers have been respite programs, support and educational groups, and more recently psychotherapeutic treatments. From the perspective of caregivers, these programs have met with resounding success. Evaluation research consistently reports users as liking the services and being satisfied with them (Gallagher 1985; Gallagher, Lovett, and Zeiss 1989; Lawton, Brody, and Saperstein 1989). From the perspective of policymakers, evaluation studies have not been reassuring in that they have failed to show a substantial impact on either burden and caregiver well-being or on desire for institutional support (Gallagher 1985; Gallagher et al. 1989; Lawton, Brody, et al. 1989; Zarit 1990). These findings have led Callahan (1989) to question the delivery of community-based services, arguing that their usefulness needs to be justified against some criterion that has policy relevance: "liking and satisfaction as rationales for long-term care services are not as compelling as food for the hungry and homes for the homeless" (p. 5).

Defense of community-based services has come from a number of sources: the infancy of evaluation research in this field (Gallagher et al. 1989; Haley 1991), the methodological difficulties associated with group heterogeneity on the criterion variables at the outset (Haley, Brown, et al. 1987; Whitlatch, Zarit, and von Eye 1991), problems of unexpected life events wreaking havoc in small intervention studies (Haley, Brown, et al. 1987), inappropriate targeting of beneficiaries (Gallagher 1985; Lawton, Brody, et al. 1989) and outcome measures that are too broad to be sensitive to the changes brought about by the intervention (Gallagher 1985; Kosberg, Cairl, and Keller 1990). Haley (1991) has encouraged researchers to resolve these difficulties, "to do their best to ignore demands for immediate, simple answers, and to persevere in work that will eventually lead to effective interventions" (p. 8). This approach is commendable, but in the short term policy-

makers must decide how limited resources are best allocated on the basis of available knowledge.

One alternative approach to establishing caregivers as a needy group stems from the arguments of George and Gwyther (1986), Schulz, Visintainer, and Williamson (1990), and Anthony-Bergstone, Zarit, and Gatz (1988). Specific measures of burden make it impossible to compare caregivers with community populations. Thus, there is no basis for arguing that caregivers experience the stress or suffer the hardships of disadvantaged groups such as the unemployed or the homeless. The solution to this problem has been to use measures of adjustment which are applicable to the general population. George and Gwyther opted for indices of well-being, while Schulz et al. and Anthony-Bergstone et al. have favored measures of psychiatric symptoms. Unfortunately, the findings of such research have been equivocal. Furthermore, measurement and sampling difficulties and the inability to control key variables confuse rather than clarify arguments concerning the extent to which caregivers deserve government support.

In general, researchers have found caregivers to have a lower quality of life and poorer mental health than the general population (Braithwaite 1990; Fengler and Goodrich 1979; George and Gwyther 1986; Gilleard 1984; Jones and Vetter 1984; Schulz et al. 1990; Thompson and Haran 1985). Yet others report few differences (Anthony-Bergstone et al. 1988; Eagles et al. 1987a, 1987b; Gilleard 1984). In interpreting these findings, a number of important deficiencies have been cited. First, the problem of obtaining a representative sample of caregivers has been raised (Morris et al. 1988; Schulz et al. 1990). Often samples of caregivers are obtained through agencies that deliver services; the resulting concern is that the bias is toward caregivers who are having difficulty coping (Schulz et al. 1990). On the other hand, the opposite problem has also been suggested: Those who are overly stressed are often unwilling to leave their homes to seek assistance and be interviewed about their problems (Dura and Kiecolt-Glaser 1990). In addition to biases in selecting the caregiving sample, consideration must be given to the consequences of unmatched comparison groups within the general population. Controlling for gender and age is relatively straightforward, but we have yet to identify the psychological factors that determine who will adopt the caregiving role. Personality variables may differentiate long-term

caregivers from other groups. Such factors may involve emotional vulnerability, which predisposes caregivers to anxiety and depression.

A further problem has been raised in relation to studies in which the adaptational measure is depression: Are caregivers exhibiting psychiatric symptoms or are their responses reflecting dysphoric mood (Becker and Morrissey 1988)? From a policy perspective, the distinction carries some weight. Governments might be expected to intervene to preserve the mental health of their citizens for both moral and economic reasons. Dysphoria, however, is a condition that has less relevance to the allocation of resources. Dysphoria suffers the same weaknesses as the burden construct: It is an emotive individualistic concept.

New Directions

Abel (1990) has been critical of the dominance of stress research in the caregiving literature because of the aspects of caregiving which it excludes and because of the restrictions imposed on policy options. Policy has become dependent on demonstrating that caregiving threatens public health, that interventions reduce stress, and that support can prolong family caregiving (see Callahan 1989). Abel moves the argument for caregiver support out of the domain of stress relief and into the domain of social justice. She maintains that the "overriding issue is . . . not how to relieve stress, but how to organize society to make care for the dependent population more just and humane" (p. 147). Particularly, she raises questions about the way in which caregiving affects women and the extent to which their opportunities are restricted through taking on this role.

As important as it is to develop caregiving research outside the stress paradigm, this article offers a reconceptualization that remains firmly in that tradition. In Abel's (1990) terms, it continues to focus on the adjustment of caregivers rather than on the social system within which the caregiving demands are embedded. At the same time, the conceptualization ties burden to conditions of living which are not generally accepted as reasonable in modern Western societies. Thus, the model of burden proposed here encompasses concerns that are not dissimilar from those expressed by Abel.

A NEEDS-BASED CONCEPTUALIZATION

As there are problems in defining burden in terms of distress, there are problems associated with burden as impact or disability. Yet, by considering impact and disability, we can gain a better understanding of the development of burden in those caring for elderly people. The impact of caregiving is well-documented. Losses have been reported in employment, financial well-being, friends, social activities, leisure activities, freedom, privacy, and sleep (Archbold 1983; Barnes, Raskind, Scott, and Murphy 1981; Cartwright, Hockey, and Anderson 1973; Equal Opportunities Commission 1980; Dunkle 1985; Grad and Sainsbury 1963, 1968; Jones and Vetter 1984; Thompson and Haran 1985). Disruption of household routine and family life also is acknowledged (Grad and Sainsbury 1963, 1968), and the difficulty of assuming new roles recognized (Barnes et al. 1981; Fengler and Goodrich 1979). Considerable effort has also been directed toward documenting the kinds of disability that caregivers find difficult. Consistently, a major cause of caregiver upset is difficult and demanding behavior (Grad and Sainsbury 1963; Robinson and Thurnher 1979; Sanford 1975).

Yet these impacts and disabilities are an integral part of caregiving in other areas of life as well. Take a newborn baby as an example. The same losses occur — one's social life is restricted, sleep is broken, work is often relinquished or compromised, savings are eroded, and freedom lost. The same changes take place — the household is thrown into a state of chaos, and family life is disrupted. An even greater level of dependency is handled with pride and affection and rarely interpreted as burden. As children grow, tantrums, biting, and other antisocial behaviors may cause annoyance and embarrassment, but parents usually show forgiveness and acceptance, dismissing the behavior as a stage they all go through. Where then does the difference lie? What is the source of burden in caring for elderly people?

The central thesis of this article is that burden is a product of caregiving which is unable to prevent deterioration of a physical, psychological, or social kind.¹ Caring for elderly people, unlike caring for a normal child, involves increasing dependency. In dealing with increasing dependency, five crises are encountered with contrast sharply with the demands made during child rearing: awareness of degenera-

tion, unpredictability, time constraints, the caregiver-receiver relationship, and lack of choice.

Independence and personal growth are highly prized in our society. As children mature and gain independence, parents experience pride and accomplishment. In contrast, as elderly people lose their independence and control, caregivers are left with feelings of hopelessness and frustration (Archbold 1983; Barnes et al. 1981; Cantor 1980; Robinson and Thurnher 1979; Strong 1984). The difference is a difference of outcomes. Involvement in child rearing leads to a socially recognized positive outcome: the emergence of a productive human being. Involvement in elder care leads to a much feared social outcome: the loss of that human being. Degeneration threatens the caregiver's sense of security and sense of accomplishment.

Degeneration is not as predictable as maturation, giving rise to the second crisis, unpredictability. As children grow, there is both knowledge that caregiving levels will systematically decrease and expectations about when developmental stages should be reached. No comparable charts outline the stages of de-development. In spite of handbooks for caregivers on various illnesses (e.g., stroke, Alzheimer's Disease), different diseases take different courses, the same disease affects different people in different ways, and the day-to-day variability within one individual with a particular disease can be considerable. For caregiver of older adults the future is particularly unpredictable (Barnes et al. 1981).

The third crisis, time constraints, affects caregivers at two levels. First, as dependency increases, caregiving falls on the shoulders of one particular person. Rarely is it a shared responsibility (Brody 1981, 1985). In contrast, sharing of care is institutionalized in normal child-rearing situations through schooling, kindergartens, and play groups, and it is provided informally through baby-sitting or going to a friend's house to play or stay over. Caregivers of those who are losing rather than acquiring skills do not have such a range of options. Where alternatives are available, no tradition exists to guide usage. The services are there for those who need help, rather than as an accepted right for all with caregiving responsibilities.

At a second level, time constraints in elder care arise because of life stage. For those caring for a parent, other responsibilities are likely to include a family and employment (Brody 1981; Treas 1977). Thus,

caring for a parent is an additional responsibility and the priorities that should be assigned to it a matter of individual choice. In the child-rearing years, problems of role overload and conflict may also be encountered, but guidelines, norms, and support structures within the society dictate and facilitate the prioritizing of child care. "Women in the middle," however, must constantly juggle their obligations to their children with their obligations to their parent and other family members. It is not surprising that caregivers experience high levels of role overload and conflict (Cantor 1980; Equal Opportunities Commission 1980; Montgomery et al. 1985).

The relationship between parents and young children is characterized by love and authority, with love being reciprocal and authority residing in the parent. No such norms govern care for an older adult. Indeed, old norms may need to be reversed in adult caregiving. Once a family member has accepted responsibility to care, no assurances can be given about whether the caregiver and carereceiver will get along in their new dependency relationship. No safeguards exist against one dominating the life of the other, and therefore the likelihood of conflict is increased. This facet of adult caregiving contrasts sharply with infant caregiving, where power relations are clearly defined.

Finally, lack of choice is a more salient issue in aged care than in child care. Child rearing can be avoided altogether or taken on at a time that suits the individual. In contrast, caregivers of the elderly are responding to the need for help in another. Given the strength of family ties, caregivers have little choice but to give and give immediately (Brody, Johnsen, Fulcomer, and Lang 1983; Shanas 1979; Sussman 1965). In so doing, they may be forced to put aside other plans, forgo activities and even undertake tasks that are beyond their capability. Taking on care for an elderly person threatens desired goals such as reentry into the work force for women and enjoyment of the golden years for retirees. Meeting these obligations may also threaten the physical well-being of those who are themselves suffering from health problems.

These five crises of decline not only contrast with the experiences encountered in normal child rearing, but they all are potentially detrimental to well-being. Furthermore, the level at which this occurs is neither quality of life nor emotional stability, though these may be

adversely affected. The threat is at the level of basic needs. Maslow (1954, 1962) has identified four basic needs: physiological, safety, love, and self-esteem. Physiological needs are satisfied through adequate sleep and diet. Safety needs refer to the desire for security and order in one's life. Love and belongingness needs are fulfilled through group membership and social relationships that are supportive of the self. Self-esteem refers to the need to feel worthy, to have self-respect, and to be satisfied with one's accomplishments. Maslow's typology is particularly relevant to caregiving, although these needs have long been recognized in other typologies as part of human being's essential psychological requirements (see Fromm 1941; Murray 1938). Maslow's notion of needs ordered in a hierarchical fashion is not adopted in this model. Basic needs may exist concurrently.

LINKING THE CRISES OF DECLINE TO NEEDS

Perceiving degeneration in the recipient of care focuses attention on death, thereby threatening stability and security for all involved in caregiving. Degeneration also highlights the transience of intimate relationships. Experiencing the demise of a close and supportive relationship while caregiving undermines belongingness and a sense of being loved. Finally, losing a partner on whom the caregiver has depended for his or her material well-being can leave a vacuum not only for meeting security needs, but also physiological needs.

Unpredictability in caregiving is likely to affect the caregiver's capacity to plan, threatening her sense of order and control. As such, safety needs are at risk of not being met. If the caregiver believes that the course of the carereceiver's disease of disability is within her control, self-esteem may also suffer.

Time constraints can be expected to threaten basic needs on two fronts. When caregiving is in competition with other commitments and responsibilities, the chances of poor performance are likely to be increased with consequent loss of self-esteem. Where competing commitments involve friendships and obligations, interpersonal relationships may become strained, and the fulfilment of love and belongingness needs jeopardized.

Interpersonal difficulties of caregivers and carereceivers are likely to undermine the sense of worth of both parties, as is lack of choice in

the caregiving role. Resentment and unwillingness to care will prevent caregivers from developing the confidence and competence they need for high self-esteem. Feeling trapped in the caring role and its associated lack of control may also threaten safety needs.

The argument presented here is that caregiving for older adults poses a far greater threat to basic needs than the normal caregiving activities in which most women engage throughout their lives. Caregiving burden is therefore defined as the extent to which the meeting of caregiving demands threatens satisfaction of the caregiver's basic needs of a physiological, safety, social, and self-esteem kind.

ADVANTAGES OF THIS CONCEPTUALIZATION

This definition identifies burden with the subjective tradition, an outcome that sits comfortably with more recent research arguing that the stress of caregiving has more to do with subjectivities than objectivities (Haley, Levine, et al. 1978; Motenko 1989; Novak and Guest 1989b; Townsend, Noelker, Deimling, and Bass 1989). At the same time, the definition restricts the domain and defines the boundaries more clearly than in past. The domain of basic needs is readily assessed by paper and pencil questionnaire (see Braithwaite 1990), through open-ended interviewing, or through observational methods.

Furthermore, the definition captures the subjective component without being emotion-laden and guilt inducing. Awareness of need frustration may be a precursor of distress (Maslow 1962) but does not necessarily involve distress. Caregivers may recognize their need for more sleep, their need for more routine, and the undermining of their confidence, yet not report emotional distress. For some the distress may lie ahead; for others it may be controlled (see Becker and Morrissey 1988). Definitions that focus on distress are neglectful of caregivers whose needs are great but who are managing to cope and keep their feelings under control.

Such caregivers also are more likely to have difficulty acknowledging burden as it is traditionally used. Linking burden with the caregiver's emotional upset or with responses to the carereceiver's impairment runs the risk of creating guilt. To tie burden to disabilities reinforces the view of the care recipient as "the burden." Associating burden with the caregiver's distress has connotations of the caregiver

being weak and inept. Both approaches are invitations to allocate blame and are guilt inducing—those being cared for feel guilty about being a burden, whereas those providing care experience guilt for not having sufficient strength and endurance. The proposed definition purports that burden is not caused by the carereceiver nor the caregiver but arises from the interaction between the two. Burden arises out of conflict between the needs of each player in the caregiving dyad: Burden is context dependent.

As part of the stress paradigm, burden is a mediating variable between the environmental stressors and the stress reaction. Psychological and social resources may interact with environmental stressors to prevent the frustration of basic needs. Additionally, they may weaken the link between the experience of burden and the development of symptoms. With this conceptualization, burden is located within the stress process as the point at which caregivers appraise their situation as one that is particularly harmful to their well-being. As such, it is consistent with Maslow's (1962) view of the effects of unsatisfied basic needs. In Maslow's terms, basic needs are deficiency needs in that they are experienced by the individual as annoying states of which he or she wants to be rid. Failure to satisfy can lead to illness; basic needs are "empty holes, so to speak, which must be filled up for health's sake" (p. 21).

As a focus for intervention studies, burden as basic need frustration offers an important advantage. It is plausible for interventions to aim to improve sleep, diet, order, social support, and self-esteem. It is neither realistic, nor perhaps even appropriate, for them to take away the pain of losing a loved one or watching the "slow extinction of . . . [a] personality" (Aronson and Lipkowitz 1981, p. 568). The present model provides a framework in which specific interventions and their limited effects can be sensitively tested.

From a policy perspective, burden as basic need deprivation is relevant to community care. Burden has been found to predict institutionalization and to be related to anxiety, depression, and quality of life (Braithwaite 1990). Burden also has been related empirically to a number of the components of the crises of decline outlined earlier. Greater burden accompanies greater degeneration, unpreparedness, time constraints, conflict-ridden relationships, and unwillingness to care (Braithwaite 1990).

Apart from being central to community care policy, burden ties directly into theories of welfare rights. This article argues that caregiving for elderly people leads to basic need deprivation of a kind exceeding that experienced in more normal caregiving contexts (e.g., child rearing). Caregiving for the aged may be a normative life experience at a certain age, but it is not normative within the life experiences of one individual. In effect, it turns earlier caregiving experience on its head. Despite the positive aspects of caregiving (Kinney and Stephens 1989a; Motenko 1989), caregivers repeatedly claim that they would “never wish this on . . . [their] children.” Acknowledgment of the positive aspects are more likely to be a tribute to the individual personalities involved than a reflection of the nature of the caregiving role itself. The conditions of work would be totally unacceptable in any paid work setting. Burden, as basic need frustration, thus leads us to consider caregiving in the context of welfare rights.

Barry (1990) identifies the central rationale for welfare as following the principle of desert in its negative form: “that those who suffer through no fault of their own have a valid claim against the more fortunate” (p. 529). He has delineated five categories of entitlement: reimbursement of special expenses, compensation for some loss other than impairment of earning capacity, payments to those who are not expected to work full-time; payment to those whose earnings fall short of some norm (regardless of means and income); and payments to those whose means or incomes are insufficient to get them above some minimum income. Burden as need deprivation focuses attention on caregivers as appropriate recipients of support under the second category. The idea underlying category 2 is that “someone who has done the state some service” and suffered for it has a just claim on the state for compensation. Compensating the war-disabled and worker’s compensation are Barry’s primary examples of this kind of benefit.

In likening caregiving burden to war injury and occupational harm, issues of choice and context need to be addressed. One could argue that caregiving is a family not a state concern, and caregiving involves choice. Choice, however, is fast diminishing in aged care. Prior to rapid growth in the proportion of the population who are elderly, institutional support was available as an alternative form of care. This option is becoming increasingly beyond the reach of families because of its scarcity and cost in many countries.

As families are forced to meet the needs of their elderly relatives, they are being asked to compromise their work commitments, either outside or inside the home or both. Careers and economic advancement are sacrificed (Scharlach and Boyd 1989) and the quality of relationships with spouse and children may be jeopardized (Smith, Smith, and Toseland 1991). Western societies, rightly or wrongly, are centered around the nuclear family. Caring for a family member may entail fewer costs if care is shared, but sharing care involves broadening the base of the nuclear family if the intimacy of home care is to be preserved. To assume that nuclear families unproblematically switch to functioning as extended families by including relatives, friends, or paid help as part of their intimate circle is sociologically and psychologically naive. Families are often reluctant to share their home life with "outsiders" (Smith et al. 1991). Such transitions are not without risk and sacrifice.

Women are particularly at risk, not only because they are more likely to become caregivers, but because they are being denied the opportunity to be something other than a caregiver. After child rearing, women are increasingly returning to the work force to take advantage of opportunities for career development and economic independence. To the extent that aged care policies do not provide viable alternatives, women who fill the gap in community care policies are providing a service for the state with sacrifice at two levels. They jeopardize satisfaction of their own basic needs, and they are deprived of opportunities for growth and development outside the caregiving situation. Burden as basic need frustration thus adds strength to policies that provide pensions and benefits to caregivers.

Conclusion

As a concept in research and policy discussions of community care, burden has been elevated to the level of an umbrella term that can take on a number of different meanings. One approach to making the term scientifically useful has been to dissect it into a number of components or dimensions. The alternative approach, and the one favored here, has been to restrict its meaning in such a way as to give the concept clear

theoretical boundaries, to make its measurement practical and economical, to integrate it within the dominant research paradigm, and to ensure that it has policy relevance. Burden as basic need frustration is conceptualized as an individual's response to caregiving demands that are unacceptable in a civilized society. The problem is not of the carereceiver's making nor of the caregiver's. It is a product of family structure and community care policy. Abel's (1990) and Dalley's (1988) recommendations for social change fit comfortably with this conception of burden. Tinkering with individual psyches and patterns of interaction are not sufficient to improve the quality of life of caregivers. We must focus on structural changes that broaden caregiving options and spread the responsibility of care if we are to make caregiving burden less of a reality.

NOTE

1. It follows from this conceptualization the caregivers of children with degenerative illnesses are also likely to experience burden. Burden in care is not unique to aged care.

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