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FAMILY CAREGIVING

In the past two decades, the role of informal caregivers in providing care to older persons and the relationship of informal caregivers to nurses and other health care providers have undergone changes as a result of sociopolitical trends. Shifting demographic patterns have resulted in a growing number of elders who require acute and long-term care. The change in the Medicare system from a retrospective cost-reimbursed system to a prospective fixed payment system has shifted the responsibility for care during recuperation, rehabilitation, and long-term disability from institutions to individuals and families in the community. Because of these changes, the long-term-care system would not be able to meet the needs of older persons without the services provided by family and other lay caregivers. Consequently, informal caregivers have come to be viewed legitimately as nurse-extenders. Informal caregivers provide most of the nursing care to elderly in long-term care; improving the quality of that care requires an empirically-based understanding of the structures, processes, and outcomes of family and informal caregiving as well as the ways in which nurses can work with informal caregivers and effect change within the caregiving relationship.

State of the Science

Numerous aspects of informal caregiving for older persons have been investigated using research techniques. In this review, the literature is divided into five categories, including: 1) characteristics of caregivers and the services they provide; 2) consequences of caregiving for the caregiver; 3) quality of family caregiving; 4) ethnicity and caregiving; and 5) nursing interventions designed to assist family caregivers.

Characteristics of Caregivers and Caregiving

A growing national data base derived from a number of sources, for example, the 1982 Long-Term Care Study conducted by the Bureau of the Census for the Department of Health and Human Services (Stone, Cafferate, & Sangi, 1987; Select Committee on Aging, 1987), the National Health Interview Survey (Doty, 1986), the Channeling Demonstration Project (Stephens & Christianson, 1986), the Massachusetts Health Care Panel Study (Branch & Jette, 1983) and other studies (Cantor, 1983; Horowitz & Dobrof, 1982; Liu, Manton & Liu, 1985; Noelker & Poulshock, 1982; Shanas, 1979; Tennstedt & McKinlay, 1989), has provided unequivocal evidence that family and friends (the informal caregiving system) are the sole care providers for about three-fourths of all community-dwelling elders. There is now documented evidence about the gender, age, marital status, employment status, health status, and living arrangements of most family caregivers. However, little is known about other types of informal caregivers.

Family Caregivers. Surveys have docu-mented a wide range of family caregiving activities. The

most commonly mentioned are instrumental services such as meals, shopping and errands, housekeeping tasks, and transportation (Tennstedt & McKinlay, 1989) and personal care services including eating, bathing, dressing, toileting, and/or getting in and out of bed or moving around inside the house (Select Committee on Aging, 1987). These surveys have helped to identify the duration and intensity of caregiving activities. In the 1982 Long-Term Care Study, for example, most caregivers had provided care from 1 to 4 years; about 20 percent had provided care for over 5 years. Over 80 percent of caregivers provided assistance 7 days a week. Primary care providers spend 50 to 60 hours per week providing care (Tennestedt & McKinlay, 1989). One particularly useful conceptualization of the intensity of family caregiving was developed by Montgomery, Gonyea, and Hooyman (1985), who suggested that the variety of tasks performed rather than the duration of caregiving responsibilities signifies the intensity of caregiving. In addition, they suggested that tasks can be staged based on the intimacy of tasks and the frequency of required contact. Using factor analysis, they confirmed seven categories of caregiving ranging from low intimacy, low frequency (e.g., walking, transportation, errands) to high intimacy, high frequency (e.g., feeding, toileting). This classification strategy has provided a method for quantifying caregiving intensity that has been helpful in explaining response variations in studies of family caregivers (Phillips, 1989a).

Studies of the relationship between caregiver characteristics and the nature of caregiving are underway. For example, studies are seeking to identify the roles of male caregivers versus female caregivers (Horowitz, 1985; McKinlay & Tennestedt, 1986; Rathbone-McCuan & Coward, 1985; Tennestedt & McKinlay, 1989), caregiver husbands versus caregiver wives (Tennestedt & McKinlay, 1989), and caregiver sons versus caregiver daughters (Horowitz, 1985) as well as to delineate the effect of special circumstances on the abilities of family caregivers to provide care. Special circumstances studied include caregiver's employment (Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987; Brody & Schoonover, 1986); size, density, and effect of the social support network (Baillie, Norbeck, & Barnes, 1988; Tennestedt & McKinlay, 1989); geographic proximity and distance (Hays, 1984; Moss, Moss, & Moles, 1985); and reasons for variations in the type and amount of informal care provided (Branch & Jette, 1983; Tennstedt, 1984). Although nurses have not contributed significantly to research in these areas, this research has helped to focus the attention of nurses on the family caregiver and the elder-caregiver dyad, distinct from older persons care recipient, as appropriate targets of study. In addition. it has pointed out the need for nurses to study methods for delivering nursing care that use nonprofessionals and to study nursing care processes so that they can be explained and their essential elements taught to others.

Four major nursing studies discussed the nature of family caregiving. Three (Archbold, 1983; Bowers, 1987; Phillips & Rempusheski, 1986) used qualitative-exploratory designs with small theoretical samples of family caregivers. The fourth (Stommel, King, Given, Given, & Collins, 1987) was quantitative-descriptive and used a sample of 255 family caregivers. The qualitative-exploratory studies focused on identifying caregiving roles from the perspective of the caregiver, rather than as defined by an outside observer or by specific caregiving tasks. Archbold (1983), for example, described two parent-caring roles in a study of caregiving daughters: care provider and care manager. Major differences were found in the ways that care providers and care managers enacted their caregiving roles and in the consequences of these roles for the caregiver. Bowers (1987) identified five categories of family caregiving: anticipatory, preventive, supervisory, instrumental, and protective care. Findings suggest that although researchers usually define caregiving very narrowly, based on enactment of specific tasks, caregivers define caregiving much more broadly and consider the time in the caregiving role to begin long before the actual performance of specific caregiving tasks. In addition, the priorities and perceptions of caregivers and "outsiders" are often strikingly different; understanding a caregiver's behavior is possible only within the context of the caregiver's frame of reference. Phillips and Rempusheski (1986) described two "role forms" displayed by caregivers, monitor and nurturer, characterized by the caregiver's definition of appropriate role behavior. Findings suggest that the role interpretation of

the caregiver is related directly to the quality of care provided by the caregiver.

The Stommel et al. (1987) study, a longitudinal investigation designed to study the reactions of caregivers to caring for dependent elderly family members, considered variables such as dependencies of the elder (physical self-maintenance and instrumental), negative reactions to caregiving, feelings of role responsibility, feelings of abandonment, impact on caregiver's schedule, impact on caregiver's health, impact on finances, involvement of caregivers, and service utilization. An initial report showed important differences in perceptions of health, emotional reactions, sense of responsibility, use of community resources, and perceptions of family support among four groups of caregivers (husbands, wives, working daughters, and non-working daughters).

Consequences of Caregiving for the Caregiver

Four aspects of the consequences of caregiving are considered here: 1) descriptions of caregiving consequences, including negative consequences, positive consequences, and caregiver needs; 2) descriptions of caregiving consequences among special populations of caregivers; 3) explanations for consequences of caregiving; and 4) descriptions of consequences that arise from system changes.

Descriptions of Caregiving Consequences:

Negative Consequences. The literature base des-cribing the negative consequences of caregiving has expanded rapidly in the past 10 years. There is unequivocal documentation that caregiving is stressful. Sources of caregiver stress include: 1) the personal limitations imposed by caregiving (restriction of social life, infringements on privacy) (Caston, Adams, & Danis, 1979; Robinson & Thurnher, 1979; Horowitz & Dobrof, 1982; Archbold, 1983; Cantor, 1983; Tennstedt, 1984; McKinlay & Tennstedt, 1986; Select Committee on Aging, 1987); 2) competing role demands of the caregiver (work conflicts, conflicts with familial obligations) (Brody, 1985; Brody, Johnson, Fulcomer, & Lang, 1983; Gibeau, 1986; The Travelers Companies, 1985; Select Committee on Aging, 1987); and 3) the elder's emotional and physical demands (disruptive behavior, physical work involved in caregiving) (Select Committee on Aging, 1987; Poulshock & Deimling, 1984, Cantor, 1983; Jones & Vetter, 1984; Johnson & Catalano, 1983). Other sources of stress less consistently documented are characteristics of the caregiving situation (specifically co-residence) (George & Gwyther, 1986), lack of social supports (Zarit, Reever, & Bach-Peterson, 1980), and the nature of the relationship between the elder and the caregiver (Cantor, 1983; Poulshock & Deimling, 1984; Phillips, 1989a,b).

Four types of caregiver strain resulting from stress have been identified (Select Committee on Aging, 1987): emotional strain, physical strain, financial strain, and family strain. Emotional strain is the most pervasive negative consequence of caregiving; parameters of emotional strain described in relationship to caregiving include symptoms of depression, emotional exhaustion, and feelings of anxiety, helplessness, and lowered morale (Cantor, 1983; Danis, 1978; Frankfather, Smith & Caro, 1981; Stephens & Christianson, 1986). Depression has been described most extensively (Baillie, Norbeck, & Barnes, 1988; Fitting, Rabins, Lucas, & Eastham, 1986; Kessler, McLeod, & Wethington, 1983; McKinlay, McKinlay, & Brambilla, 1987; Pruchno & Resch, 1989; Tennstedt & McKinlay, 1989). Empirical support of physical strain among caregivers is, according to the Select Committee on Aging Report (1987), "weak and equivocal." The 1982 Long-Term Care Study demonstrated that the self-assessed health status of caregivers was poorer than a comparison group of non-caregiving age peers in the general population. In contrast, other studies found that caregiver's self-assessed health status is comparable to (George and Gwyther, 1986) or better than (Danis, 1978) comparison groups of non-caregivers. In the Tennstedt and McKinlay study (1989), predictors of poor health status among caregivers included the number of involved

caregivers (sole care providers had poorer health), social class (those in lower social classes had poorer health), sex of the elder (those who provided care to men had poorer health), relationship of caregiver (spouses had poorer health) and amount of care (those providing constant care had poorer health). Deimling and Bass (1986) reported that self-assessed change in caregiver's health since becoming a caregiver was best explained by elder's activities of daily living (ADL) limitations suggesting that those who provided the highest levels of care had the greatest change in physical health.

The 1982 Long-Term Care Study is one of the few studies that specifically considered financial strain. Overall, study findings suggested that the direct financial strains of caregiving are less than anticipated. However, the report also suggested that indirect estimates of financial strain have been poorly studied; thus, conclusions about the effects of financial strain among caregivers cannot be reached until factors such as lost wages due to missing or quitting work to provide care, lost insurance coverage, and lost retirement benefits are considered in population-based studies. Family strain has been described as it affects: the caregiver; the caregiver's relationships with "other" family (spouse, children and siblings); and the relationship between the caregiver and older persons care recipient. Again, the conclusions of these studies are equivocal. For example, time spent away from other family members as a result of caregiving responsibilities has negative effects on caregivers (Archbold, 1983; Stephens & Christianson, 1986). There is, however, no conclusive empirical evidence that time spent away from other family members results in family disruption in the "other" family system. In fact, several studies (Horowitz & Dobrof, 1982; Cantor, 1980) have shown the opposite to be true. Archbold (1981) and Frankfather, Smith, and Caro (1981) showed that caregiving can result in conflict among siblings resulting in family strain. With the exception of a few studies (Archbold, 1983; Noelker & Poulshock, 1982; Phillips & Rempusheski, 1986; Barusch, 1988), little has been described about strain resulting from conflict between older persons care recipient and the caregiver.

Caregiving burden is the most frequently referred to negative consequence of family caregiving and, overall, the least well-defined. In 1972, Fatheringham, Skelton, and Hoddinott formulated a definition of caregiving burden that often is referenced in the gerontological literature; that is, caregiving burden comprises specific changes in the lives of caregivers that result from being required to provide care. In 1980, Zarit, Reever, and Bach-Peterson developed a 29-item self-report inventory that operationally defined the concept of caregiving burden as discomforts arising from the areas "most frequently mentioned by caregivers as problems, including caregiver's health, psychological well-being, finances, social life, and the relationship between the caregiver and the impaired person" (Zarit, Reever, & Bach-Peterson, 1980, p. 651). Whereas Fatheringham et al. (1972) had defined burdens as life changes, Zarit et al. (1980), defined burdens as discomforts. Progress in ameliorating problems in the gerontological caregiving literature associated with the differing definitions of the concept of burden has been made in the past decade. Thompson and Doll (1982) are credited with dichotomizing caregiving burdens into objective and subjective burdens. Platt and Hirch (1981) also are credited with emphasizing the importance of separating the events, happenings, and activities (i.e., objective burdens) from the feelings, emotions, and attitudes associated with the events (i.e., subjective burdens). More recently, Poulshock and Deimling (1984) conceptualized and investigated caregiving burden as a multidimensional concept having three categories: elder impairment, burden, and impact. Elder impairment comprised two categories: physical impairment (dependency associated with physical illness) and mental impairment. Categories of mental impairment were defined as sociability or level of cooperativeness, disruptive behavior, and cognitive incapacity, which reflects the more conventional measures of cognitive problems of older persons such as forgetfulness.

Description of Caregiving Consequences:

Positive Consequences. The research base des-cribing positive consequences of caregiving is

much less extensive than that describing negative consequences. The 1982 Long-Term Care Study examined the benefits of caregiving and found that about 75 percent of caregivers sampled felt useful as a result of being a caregiver. This finding is consistent with Doty's (1986) research report. In addition, the caregivers indicated that caregiving improved their sense of self-worth, and that the elder they cared for was a major source of companionship. A small number indicated that the elder provided assistance with household chores, child-rearing tasks, and finances. Two other positive consequences of caregiving noted in research studies are: personal affirmation of the caregiver through the caregiving experience, and personal meaning gained through the caregiving experience. Personal affirmation was recently investigated by Lawton et al. (1989) in a study of caregiving satisfaction, caregiving mastery, caregiving ideology, perceived caregiving impact, and subjective caregiving burden that tested a proposed framework of caregiving appraisal derived from the work of Lazarus and Folkman (1984). Although results did not confirm the theoretical structure unequivocally, findings suggested that caregiving satisfaction is a viable concept for future investigation. The notion of caregiving "uplifts" (Lawton et al., 1989)) is similar to Hirschfeld's (1978) identification of "small daily events" that provide the caregiver with pleasure or affirmation. Personal meaning gained through the caregiving experience has been studied by several investigators (Archbold, 1981; 1983; Bowers, 1987; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilen, 1990; Hasselkus, 1988; Horowitz, 1985; Horowitz & Shindelman, 1983; Motenko, 1989). Hasselkus (1988) used an ethnographic approach to identify themes of meaning that included: 1) sense of self; 2) sense of managing; 3) sense of future; 4) sense of fear and risk; and 5) sense of change in role and responsibility. Motenko (1989), in a study of wife caregivers for Alzheimer's patients, found that continuity is a key concept in whether or not there is meaning in the caregiving role. Motenko suggested that meaning is associated with the reciprocation of past attentions and with a sense of enduring, meaningful marital relationships despite the presence of a dementing disorder. Farran et al. (1990) used existentialism as a framework for a quantitative and qualitative longitudinal study of how caregivers of demented elders find meaning in and perceive the caregiving experience. In an initial report of qualitative findings, they described two major categories of existential aspects of caregiving associated with meaning: 1) loss, powerlessness, and external and internal philosophies; and 2) caregiver coping strategies. The first category documented the existential theme of finding meaning in suffering. The second category documented the existential themes of persons assuming responsibility for right action and conduct, and persons finding answers to challenges. Findings suggested that, despite its "strenuous" quality, caregiving provides a growth experience for many individuals. Despite these preliminary efforts, little is known about the positive consequences of caregiving, the relationship of positive consequences of caregiving and caregiver's health, or the relationship of positive consequences on the outcomes of caregiving for the elder (including institutionalization and the quality of care).

Description of Caregiving Consequences:

Needs of Caregivers. The research base that des-cribes the needs of caregivers is extremely scant. The DeAngelo (1988) study identified needs for emotional support, knowledge and concrete services, social support, and financial resources. The Snyder and Keefe (1985) study identified needs for regular respite, short-term respite, home nursing assistance, housework, emotional counseling, transportation, legal counseling, and support groups. The needs for social and instrumental support were studied by Johnson (1983) and by Jones and Vetter (1984). Although much has been written in the nursing literature about the needs of caregivers, most specifically their educational needs (Hirst & Metcalf, 1986; Rew, Fields, LeVee, Russell, & Leake, 1987), the empirical base supporting the assertions made is virtually non-existent. It could be assumed that explication of caregivers' needs is unnecessary because the study of needs is implicit in studies of caregiving consequences for the caregiver (e.g., studies that document high stress among caregivers imply the need to identify and reduce sources of stress). However, lack of explicit study of caregiver needs as perceived by the caregivers may result in suggestions for intervention that greatly miss the mark. Buckwalter (1988) and others (Yankelovich, Skelly, & White, 1986;

Caserta, Lund, Wright, & Redburn, 1987) documented the problems of caregivers not using services offered to them or dropping out of intervention programs. It is likely that, for the non-users and drop-outs, the services and programs do not meet the caregivers' needs. Explicit attention to identification of the educational, personal, and interpersonal needs of caregivers is required to assure that interventions offered are congruent with the needs of caregivers as perceived by caregivers.

Descriptions of Caregiving Consequences

Among Special Populations of Caregivers. Care-givers of Alzheimer's victims or demented elders have received the most attention from researchers. An excellent review of the literature in this area, recently published by the National Institute of Mental Health (Light & Lebowitz, 1989), discusses issues related to: Alzheimer's disease and family research; caregiver stress (the mental health/health interface); treatment and management of Alzheimer's disease patients; and mental health service research. Research conducted with caregivers of Alzheimer's victims extensively documents the stress, burdens, and other negative consequences (e.g., depression) associated with caregiving for this group (Chenoweth & Spencer, 1986; Cohen & Eisdorfer, 1988; Deimling & Bass, 1986; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Liptzin, Grob, & Eisen, 1988; Motenko, 1989; Pruchno & Resch, 1989; Quayhagen & Quayhagen, 1988; Winogrond, Fisk, Kirsling, & Keyes, 1987; Zarit, Todd, & Zarit, 1986). It also documents that likely sources of negative consequences are the caregiver's need to manage unpredictable, antisocial, and disruptive behavior patterns; the need to manage daily personal care activities (Chenoweth & Spencer, 1986; Quayhagen & Quayhagen, 1988; Rabins, Mace & Lucas, 1982); and the need for factual information about disease progression and realistic expectations for the caregiving experience (Chenoweth & Spencer, 1986). In other words, nursing problems (i.e., problems customarily treated and managed by nurses in institutional settings) are responsible for many of the negative consequences of family caregiving for Alzheimer's patients; however, nursing research in this area is negligible. Of the hundreds of references in the Light and Lebowitz (1989) report, only twelve refer to published nursing literature (Alverman, 1979; Burnside, 1983; Goto & Braun, 1987; Hirschfeld, 1983; Lucas, Steele, & Bognanni, 1986; Mace, 1985; Pajk, 1984; Rader, Doan, & Schwab, 1985; Ridder, 1986; Salisbury & Goehner, 1983; Schwab, Rader, & Doan, 1985; Williams, 1986). Most of these are informational or editorial, and few relate to care outside of the institutional setting. Clear documentation of the contribution of nurses to the nursing care needs of demented elders and caregivers at home is lacking.

Although caregivers of demented elders have been the focus of much research, considerably less attention has been given to caregiving within other special populations. Special populations that require future attention include rural caregivers and caregivers of chronically mentally ill and mentally retarded elders.

Explanations for the Consequences of Caregiving. Although the majority of studies have been conducted to describe the stresses and strains of caregivers and caregiving, a few recent investigations tested theoretical explanations for the consequences of caregiving and the propensity of caregivers to initiate and maintain the caregiving role. Unlike the purely descriptive research that assumed the problems and stresses of caregiving were sufficient to explain negative consequences, these explanatory studies sought to operationalize concepts identified in early investigations of intergenerational relationships (e.g., filial obligation, affectional ties, reciprocity) (Brody, 1985; Troll, 1971; Shanas, 1979; Troll, 1988) and to study their relationship to outcomes (e.g., willingness to give care, negative feelings).

Reciprocity, affection, filial obligation, and attachment are concepts that have been studied in an effort to explain the initiation and maintenance of helping behavior among family members. Horowitz and Shindelman (1983) studied the relationships of reciprocity and affection to

caregiving involvement and caregiving consequences; specifically, "the emotional strain, and the adverse effects in various spheres of personal and family life" (p. 9). Their findings suggested that feelings of affection provide some explanation for both the amount of caregiving involvement and the lack of negative caregiving consequences. However, reciprocity provided a plausible explanation for only caregiving involvement. Cicirelli (1983) studied children's feelings of attachment, attachment behaviors, feelings of filial obligation, interpersonal conflict with the elder, and elder's dependency as they related to present helping behaviors, future helping behaviors, and negative feelings. Cicirelli's findings suggested that children demonstrate attachment behavior (living close and keeping in touch) as a result of feelings of attachment (e.g., feeling close, values agreement, compatibility), filial obligation, and dependency of the elder. Feelings of attachment and filial obligation, however, are not related to present helping behaviors. Present helping behavior is explained by attachment behaviors and dependency of the elder. Future helping behaviors are predicted by attachment behaviors, present helping behaviors, feelings of attachment, dependency of the elder, and lack of interpersonal conflict. Negative feelings are associated with interpersonal conflict, high amounts of present helping behaviors, low feelings of attachment, low attachment behaviors, and high dependency of the elder.

Consequences of Caregiving that Arise as a Result of System Change. Although the health care system has undergone remarkable changes in the past 10 years, studies describing how these changes have affected family caregivers and family caregiving are scant. Only two examples were found in the literature. In a study by Fischer and Eustis (1988) on the impact of Diagnostic Related Groups (DRG's) on family caregiving roles, two small, nonrandom samples of family caregivers and elders, interviewed 4 years apart (1982 vs. 1986), were compared. A major difference in the descriptions of the caregiving role given by these groups was the emergence of a phenomenon the researchers identified as "The Managerial Family," that had three salient role responsibilities: family as mediators, family as supervisors, and family as planners. Hooyman, Gonyea, and Montgomery (1985) surveyed 80 caregivers for terminated and continued chore service clients and determined that service termination had no effect on the extent of caregiving, types of caregiving behaviors, perceived burdens, or the caregiver's level of stress. The authors suggested that whether or not chore services were provided, the caregivers surveyed already were providing the maximum amount of care they were willing or able to provide. In addition, the authors suggested that stress and burden were associated with personal care services that were unaffected by the presence or absence of government-supported chore services.

Quality of Family Caregiving

Although most long-term home care is provided by informal care providers, no external regulatory mechanisms exist to monitor the quality of this care. Substantial evidence suggests that the quality of informal home care is adequate to meet the needs of some care recipients; the quality of informal home care, however, varies widely. Research indicates that: 1) the quality of care is less than optimal for many care recipients, resulting in unmet physical, emotional, and social needs; and 2) some care recipients are at high risk for abuse, neglect, and other forms of maltreatment by their informal care providers (Giordano & Giordano, 1983; Hickey & Douglass, 1981a, 1981b; Lau & Kosberg, 1979; O'Malley, Everitt, O'Malley, & Campion, 1983; Phillips, 1983a; Pillemer 1985, 1986; Pillemer & Finkelhor, 1988; Steinmetz, 1981; Wolf, Godkin & Pillemer, 1984; Phillips, 1983b, 1989b).

The study of quality of care is complicated by several factors. Researchers and clinicians have failed to define operationally both extremes of the quality of care continuum for informal care providers. By default, adequate to excellent care has been defined by the absence of abuse or neglect. Operational definitions for abuse and neglect, however, are neither definitive nor clear and, clinically, these definitions are known to be confounded by legal issues such as degree of intent, amount of harm, and assignment of blame (Johnson, 1986; Phillips, 1989a). Some

clinicians have tried to circumvent these problems by defining quality of informal home care by the degree to which the recipient's needs for physical and/or emotional support are met by the informal care providers (O'Malley et al., 1983; Phillips, 1989a). There is, however, no appropriate measurement standard against which the care provided by informal care providers can be judged. Without a measurement standard, judgments about the adequacy of home care will continue to be confounded by variables such as socioeconomic status, ethnicity, and the care recipient's personal characteristics. Unlike care provided in hospitals, care outcomes in the home rely primarily on the skills and expertise of family members and secondarily on the counseling and educational roles of the nurse (Baines, 1984; Clark & Rakowski, 1983; Dunn et al., 1986; Hirst & Metcalf, 1986; Kitson, 1986; 1987a,b; Mann, 1985). This presents a special dilemma for the evaluation of quality indicators. Although quality of home care has recently been discussed in the literature, articles focus primarily on evaluating the care provided by professionals or nonprofessional staff (Daniels, 1986; Mumma, 1987).

Other factors also contribute to the problems of studying the quality of informal home care. For example, there are currently no acceptable alternatives for the service provided by the informal care system. Therefore, substandard care generally is tolerated and, to some degree, supported if identifying that care as less than adequate could jeopardize the living arrangements and autonomy or independence of the care recipient. In addition, prevailing social attitudes dictate against questioning the "good intentions" of family members or violating the sanctity of the home setting. Monitoring the quality of home care generally is viewed as the responsibility of the care recipient and/or the care recipient's family regardless of whether they are physically or emotionally capable of assuming that responsibility. These factors have made it difficult to estimate the scope of the problem of poor quality informal home care. Some research has focused on identifying the incidence of frank elder abuse with estimates ranging from 4 percent (Pillemer & Finkelhor, 1988) to 23 percent (Steinmetz, 1983). From clinical observations and from discussions with home health nurses and adult protective service workers, it is clear that although these figures provide some information about the incidence of frank abuse, they seriously underestimate the incidence of poor quality informal home care.

Despite the complications involved in studying the quality of informal home care, some efforts have been made to study both process and outcome. There are several reasons why study of the processes of informal caregiving is particularly appropriate for nurse-researchers. First, nursing is process and the ability of nurses to effect positive caregiving outcomes is related to how care is provided as much as to what is actually done. Second, most in-home care is done by lay caregivers who must be taught both what to do and how to do it. Thus, effecting positive outcomes for home-bound elders is possible only if care processes can be clearly identified and effectively taught to lay caregivers.

Informal Caregiving Processes. Several nurse-researchers have developed theoretical models to explain the dynamics of informal care processes (Archbold, 1981, 1983; Bowers, 1987; Phillips & Rempusheski, 1986). Bowers' (1987) theory explains caregivers' behaviors in terms of their reconstructing the meaning of certain events (for example, an episode of forgetfulness) to alter the event so that it is consistent with the elder's personality and personal characteristics. Thus, many behaviors displayed by caregivers that could be interpreted by health care professionals as unrealistic or uncooperative are motivated by a desire to protect the elder's self-esteem and sense of integrity. The consequences for the caregiver are isolation from resources seen as threatening to the integrity of older persons individual. Phillips and Rempusheski (1986) developed a theory of family caregiving that focused on the interactional and historical context of caregiving as related to quality. Phillips (1989b) showed that certain concept of the theory (discrepancy between the caregiver's past and present image of elder, role definition, monitoring and role definition, assessing and nurturing) explain variance in the quality of informal caregiving, particularly for cognitively unimpaired elders. None of the situational variables tested (caregiver's social supports,

elder's cognitive impairment, elder's ability to perform ADL's, and caregiver's stressful life events) directly affected the quality of informal caregiving, although caregiver's stressful life events and elder's ability to perform ADL's had an indirect effect on quality of care through subjective perception of caregiving burden. When both situational and interactional variables were considered, one situational variable (caregiver's stressful life events) and one interactional variable (discrepancy between the caregiver's past and present image of the elder) directly affected the quality of informal caregiving. Both of these plus caregiver's social supports and the elder's ability to perform ADL's had an indirect effect through the caregiver's subjective perception of burden. This study facilitated development of several measurement instruments to quantify aspects of the interactional context of informal caregiving (Phillips, Rempusheski, & Morrison, 1989) and development of an observational measure for quantifying the quality of informal caregiving (Phillips, Morrison & Chae, 1990).

Informal Caregiving Outcomes. Traditional outcome indicators used to measure the quality of informal caregiving have been 1) lack of institutionalization (Zarit, Todd, & Zarit, 1986); 2) change in functional or affective status of the elder (Sherwood, Morris, & Ruchlin, 1986); and 3) change in functional or affective status of the caregiver (Winogrond, Fisk, Kirsling, & Keyes, 1987; Hooyman, Gonyea, & Montgomery, 1985). Problems are associated with each of these outcome measures. Lack of institutionalization, for example, is designated as an outcome indicator based on the assumption that institutionalization is a poor caregiving alternative, a "treatment failure." There is no empirical evidence, however, suggesting that this assumption is true or that home-based care is a "better" care alternative than institutional care. In general, there are problems with the sensitivity of measurement techniques and with experimental control of the independent variable; techniques that control experimental conditions to assure validity must be developed. In addition, how much change and what kind of changes are possible, given the caregiving situation and the physical and emotional status of both the elder and caregiver, remain to be determined.

Studies of elder abuse and neglect provide other examples of outcome indicators that have been used to denote the quality of informal caregiving. Variables that have been linked with elder abuse and neglect include: 1) structural factors (e.g., social isolation, economic strain); (2) elder-related factors (e.g., physical and emotional dependency, poor health, impaired mental status, a "difficult personality"); and 3) caregiver-related factors (e.g., life crises, exhaustion, substance abuse) (Block & Sinnott, 1979; Hickey & Douglass, 1981a, 1981b; Lau & Kosberg, 1979; Rathbone-McCuan & Voyles, 1982; O'Malley et al., 1979; Phillips, 1983a; Steinmetz, 1983). Many of these factors, however, were identified in early studies of elder abuse that had severe methodological limitations (Pedrick-Cornell & Gelles, 1982). More recent investigations (Phillips, 1989a; Pillemer, 1986; Giordono & Giordono, 1983) failed to support uniformly the relationships identified in the early studies. Nurse-researchers have developed and tested a number of assessment instruments for identifying elder abuse, high-risk caregivers, and high-risk caregiving situations (Falcioni, 1982; Ferguson & Beck, 1983; Sengstock & Hwalek, 1986; Fulmer & Cahill, 1984). Fulmer, in particular, has made important strides in developing and testing standard assessment and treatment protocols for abused elders (Fulmer,1989; Fulmer & O'Malley 1987). Johnson (1986) and Hudson (1989) contributed to deriving operational definitions of elder mistreatment and to explaining the cognitive processes that promote or inhibit the health care provider's ability to diagnose and intervene in individual cases of elder abuse (Phillips & Rempusheski, 1985a,b).

Descriptions of Ethnicity and Caregiving

Overall, studies that focused on caregiving within ethnically unique groups (Chatters, Taylor, & Jackson, 1985; 1986; Cohler & Lieberman, 1979; Guttman, 1979; Markides, Bolt, & Ray, 1986; Markides & Kraus, 1985; Mostwin, 1979; Zambrana, Merino, & Santana, 1979) documented that reliance upon family members for elder care or use of the informal care network is a common

pattern among all ethnic groups in the United States, including "Old Yankee Americans." Mexican-American families have been found to be extremely supportive and protective of their elders (Carp, 1968; Markides, Hoppe, Martin, & Timbers, 1983). This tendency apparently is rooted in several key characteristics of Mexican-American families including centrality of the family, expectations for mutual aid and support, and age hierarchy (Maldonado, 1979). Some investigators suggested that this high degree of support and protection has both positive and negative elements, with Mexican-American elders being isolated from community-based services (Cuellar, 1978; Maldonado, 1975), and Mexican-American elders frequently expecting more than their children are able or willing to provide (Markides, Hoppe, Martin, & Timbers, 1983). Extensive kinships have been identified among black families (Chatters, Taylor, & Jackson, 1985; Martin & Martin, 1978; Taylor, 1985), with black elders frequently receiving gifts, assistance when ill, and transportation from family members (Chatters, Taylor, & Jackson, 1985; Taylor, 1985). Elderly black women tend to receive more assistance and support than elderly black men. Similar patterns of care provision have been found among white ethnics (e.g., Jewish, Greek, Hungarian, Latvian, Estonian, Lithuanian, Italian, Polish) (Guttman, 1979), with family members, particularly living children, being the most important sources of support.

Some studies have compared caregiving among various ethnic groups. Cantor's (1979) classic study, for example, showed that white Americans and black Americans resemble each other, in terms of care provided and family-designated caregivers, more than either group resembles the Mexican-Americans. Pacheco (1985) found significant differences between Anglos and Mexican-Americans in the ways that children behave and feel toward their parents, with Mexican-Americans feeling closer and having more frequent contact than Anglos. Markson (1979) showed that patterns of institutionalization for Mexican-Americans and black Americans resemble each other, with elders in these ethnic groups being significantly underrepresented in institutions. Although various explanations can be given (including lack of institutional alternatives, lack of economic resources to finance institutionalization, unwillingness to institutionalize regardless of the circumstances), it is clear that families in these two ethnic groups provide proportionally more home care for impaired elders than do whites. Markson (1979) also found that when compared with "Old Yankee Americans," newly immigrated, non-English speaking white ethnics of all types were overrepresented in institutions regardless of the availability of family members to provide care; however, this effect disappeared after the second generation. This finding was supported by Guttman (1979) who showed that among white ethnics, differences in caregiving patterns were more related to time since immigration than to specific type of ethnic group. Kent (1971) and Rosenthal (1986) suggest that age might be the great "leveler" with regard to ethnocultural differences. It is clear that differences do exist in caregiving behaviors based on ethnicity. It is not clear, however, that ethnocultural influences are the sole determinant of the differences observed, or to what degree ethnicity and culture affect either perceptions of caregiving burdens or the quality of elder caring being provided. Research in these areas is virtually nonexistent.

Nursing Interventions Designed to Assist Family Caregivers to Older Persons

Nurses play a central role in the delivery of services to family caregivers through their work in the home, clinics, day and respite care settings, and in-patient facilities such as nursing homes. However, the pressing need for services has meant that there has not been time to evaluate systematically many of the intervention strategies designed to assist families in caregiving situations. Little data exist to indicate whether or not a particular nursing intervention strategy is effective, and no data exist to assist in targeting interventions. For example, it would be useful to know which caregiver and family characteristics are indicators for a particular intervention, or at what time in a caregiving trajectory an intervention should be applied. Three articles reviewed evaluations of interventions with family caregivers for frail older persons (Clark & Rakowski, 1983: Gallagher, 1985; Gallagher, Lovett, & Zeiss, 1989). Gallagher et al. (1989) grouped intervention programs for caregivers into four conceptually distinct types based on the nature of

services provided: respite programs, peer-led support groups, professionally-led education and support groups, and counseling or psychotherapy.

Research Needs and Opportunities

Characteristics of Caregivers and Caregiving

The general lack of attention by nurse researchers to describing caregiving activities has resulted in a significant gap in the literature. Although the nature of daily living services provided to elders is fairly well-documented, little is known about the nature of skilled nursing services provided to elders by family members. For example, even though the 1982 Long-Term Care Study included questions about services such as medication administration and bandage changes, the complexity of these activities and the nature of the knowledge required by family caregivers to successfully and safely manage their skilled nursing responsibilities have not been documented clearly. With the recent changes in Medicare policies and the rapid discharge of elders from hospitals to home following acute illnesses, the level of acuity of elders at home has risen sharply, making this research area even more important. In addition, nurse-researchers are just beginning to describe the processes involved in family caregiving and the way in which these processes affect the caregiver, the elder, the caregiver-elder dyad, and the relationships among the caregiver, the elder, and the health care community. Continued study in these areas is essential to expand our understanding of the manner in which care is provided at home and to design intervention programs that improve caregiving outcomes.

Consequences of Caregiving for the Caregiver

An extensive body of research exists describing the consequences of caregiving for the caregiver. Based on this research and on the repeated demonstrations that caregiving is stressful, especially caregiving for demented elders, it is hard not to agree with Zarit (1989) who questions the need for another descriptive study of stress and caregiving. However, despite the extensiveness of the research base and the uniformity of some findings, there are remarkable inconsistencies in other findings of these studies. Several reasons for these inconsistencies have implications for future research. First, there has been a tremendous overall lack of consistency in the definitions and measurement methods used, for example, definition of and measurement of caregiving burden. Second, the majority of these studies used small samples. Most researchers have been satisfied sampling any caregiver who would respond and little attempt has been made to differentiate the responses of spouses from children, those who live together from those who live apart, or those who care for mentally impaired elders from those who care for mentally unimpaired elders. Studies that have made these differentiations have demonstrated more consistent patterns. The need for precise subject selection criteria and precise categorizations of data according to type of caregiver cannot be overemphasized. Third, studies describing the consequences of caregiving have been theoretical, with a few notable exceptions. Although some theoretical frameworks have been used (e.g., Lazarus and Folkman's Coping Framework has been popular as have the intergenerational frameworks proposed in the 1960's and 1970's--social exchange theory and symbolic interactionism), the frameworks have been used to explain isolated findings. Few attempts have been made to develop or test unified explanatory theories of the consequences of caregiving.

Fourth, the descriptions that have been generated are limited in scope. The survey methods used have focused on simplicity rather than complexity. The consequences of caregiving are multidimensional. Simple correlational studies are not sufficient to explain the multicausal or nonrecursive relationships that truly reflect the complexity of caregiving. Fifth, for the most part, caregiving has been studied from the perspective of the investigator and not from the perspective of the caregiver. Although there are notable exceptions, the majority of the research assumes that

an "outsider's" interpretation of caregiving is true; experience from the perspective of those who are living it is largely ignored. Sixth, most studies of caregiving have been cross-sectional; longitudinal studies of caregiving are few. One reason for conflicting findings may be that the consequences of caregiving, the coping styles used by caregivers, the needs of caregivers, and the dynamics of caregiving are influenced greatly by the stage of caregiving. Thus, efforts to understand these factors will be limited until salient stage markers for the caregiving process have been identified. Based on the complexity of the caregiving process, simple markers such as length of caregiving and nature of task being done by the caregiver are likely to be less salient than the identification of universal developmental milestones in the caregiving process. Last, the setting in which caregiving occurs (the home) and the performance of tangible services have defined the nature of informal caregiving. As a result, the nature, consequences, and dynamics of caregiving that occurs either in the community prior to the provision of tangible services in the home or after institutional placement are largely unknown except for the work of a few investigators such as Buckwalter & Hall (1987) and Matthiesen (1988). Qualitative studies (Bowers, 1987) suggest that, from the caregiver's perspective, the caregiving role transcends settings and tasks. Studies of caregiving that use a broader definition of the caregiving experience than has been used to date are required.

Although nurse-researchers have not contributed extensively to the body of research describing the consequences of caregiving for the caregiver, nurse-researchers have unique contributions to make in this area based on the scope of nursing practice. First, though much attention has been given to the needs of caregivers in the nursing literature, the empirical base that underlies these recommendations is virtually non-existent. Knowledge of the problems of caregivers does not delineate the needs of caregivers. Attention should focus on identifying and describing the needs of caregivers and on designing intervention strategies to meet these needs. This gap in the literature is particularly acute with regard to educational needs of caregivers and teaching strategies that are effective with this group, and with regard to the needs of caregivers that result from the impact of care delivery systems on care processes in the home. Second, nurse-researchers can make a unique contribution to describing and explaining the negative and positive consequences of caregiving from the perspective of the family caregiver. Nurses have a long tradition of providing in-home services to frail elders and the families who care for them. Nurses have intimate knowledge of the difficulties involved in providing care and, as a consequence, have the potential for close empathic ties with the caregivers. To a large degree, the knowledge that we have of the consequences of family caregiving for the caregiver is static, sterile, and theoretical. Although it offers a starting point for understanding the scope of the problem, it does little to identify the richness, diversity, or complexity of "real life" caregiving situations. Possibly the most important contribution that nursing research can make to this area is to translate clinical knowledge about the holistic nature of caregivers, caregiver-elder dyads, and caregiving into dynamic, testable, and tested theories that account for the factors that explain the consequences of caregiving and that identify feasible and effective interventions.

Quality of Family Caregiving

Little explicit attention has been paid to the issues of structure or access. These areas are particularly promising for future nursing research. Some attention is being given to the issues of process and outcome as quality indicators Overall, the explication and quantification of the processes and outcomes of informal caregiving are very promising areas of inquiry for nursing research. Work in these areas has begun, but continued and expanded emphasis is likely to result in improvements in both home care and long-term care in institutions. The development of outcome indicators that consider both cost and quality is an important area for nursing investigations. Nurses currently play an important role in providing services, case-managing services for caregivers and home-bound elders, and teaching caregivers to provide services. Their roles require that they identify high-risk clients and use the major intervention strategies available

(one-to-one counseling, education, support group participation, respite care, and in-home support services). Though they carry out these responsibilities as part of their role definition, the research on which decisions about inter-vention and service provision are based is scant and documen-tation that a relation-ship exists between services rendered and outcomes achieved is conflicting. Further-more, the outcome in-dicators currently being used to measure success of intervention (e.g., reduction in stress, reduction in burden, reduction in depression, functional improvement of the elder, lack of insti-tutional placement for the elder, cost-effectiveness in relationship to out-come) are, at best, imprecise and fairly insensitive to the changes that are likely to result from intervention. This is a particularly important area for nurse-researchers in the future.

Ethnicity and Caregiving

Although some data-based descriptions of caregiving among minority groups have been generated, this area remains an extremely important one for future study. There are undoubtedly similarities among minority caregivers and others; however, there are probably striking differences as well. Research aimed at identifying and explaining these similarities and differences is essential before it will be possible to design and test nursing interventions that effectively meet the needs of family caregivers in various ethnic groups.

Courtesy, Benjamin Rose Institute, Cleveland, OH

Nursing Interventions

Most of the early work in this area includes anecdotal accounts of the effects of new interventions using a small number of self-selected volun-teers. Most research has focused only on program evaluation or client outcomes and rarely have both of these been considered in the same study. Consequently, cost parameters, for ex-ample, have not been part of the data ana-lyzed in most clinical trials. In addition, only recently have investigators begun clinical trials that should help us to understand whether a particular service is effective, for whom, at what point in the caregiving process, and under what cir-cumstances. Research to determine why specific caregivers do or do not use certain types of services as opposed to others is absent except for that being conducted by Stommel et al. (1987). Most interventions that have been evaluated used a group as the target of the intervention. The majority of nursing interventions with caregivers, however, are done on a one-to-one basis in a home or institutional setting. For example, one major focus of the nurse-caregiver interaction is designed to enhance the individual caregiver's ability to perform the specific caregiving activities required by the care receiver. Another focus is on the modification of the specific home environment so that caregiving can be done more effectively and with less potential for injury. Nursing interventions such as these are by nature more sensitive to the specific caregiving situation and the context within which caregiving is experienced by the dyad than are group interventions. Evaluations of these nursing interventions are absent from the literature. Therefore, nurse-researchers need: 1) to expand their efforts in studying the management of behavior problems among older persons; and 2) to design studies that test the effectiveness and transferability of management strategies developed in institutional settings to the home.

Standardized instruments to measure key concepts in caregiving are needed for investigators interested in evaluating the efficacy of nursing interventions for caregivers. Although some tools are available to measure the negative consequences of caregiving (Gallagher, 1985; Montgomery, Stull, & Borgatta, 1985; Robinson, 1983; Zarit, Reever, & Bach-Peterson, 1980), no standardized instrumentation is available for many variables that are central to understanding caregiving

phenomenon (e.g., the nature of the caregiving role, the care receivers). Further, the clinical usefulness of existing measures has not been determined. Also, existing instruments have not proved sensitive enough to detect changes brought about by such interventions as respite. Similarly, the methodological issues inherent in conducting clinical trials are poorly developed within nursing.

Our knowledge base related to caregiving interventions is still too tentative to understand whether or not a specific nursing intervention will be effective with caregivers in general, and much too fragile to know with any certainty which

individual and family characteristics will be associated with the effectiveness of a particular intervention. Yet, there is reason to believe that nursing research directed toward the evaluation of interventions with individual caregivers and care receivers may make a significant difference in the everyday lives of these persons. The issue of targeting interventions is very important for clinicians who, with little or no information, must make decisions regarding service recommendations to caregivers.

Recommendations

Based on the foregoing assessment of research needs and opportunities in "Family Caregiving," the Panel has made the following recommendations for research.

Investigate the processes and outcomes of caregiving, focusing on 1) the caregiver's perception of needs and the meaning caregivers ascribe to the caregiving experience; 2) the formulation of testable theories and testing of theoretical models that account for both process and outcome; and 3) the caregiving process from a longitudinal perspective (not necessarily setting- or task-specific).

- Develop and refine standardized measure-ment instruments and methods in caregiving research to facilitate evaluation of the efficacy of nursing interventions for caregivers.
- Evaluate the efficacy of personal care and environmental and behavioral management methods that have implications for or are conducted in other than institutional settings.
- Investigate caregiving among special populations, particularly among minority groups and those living in rural settings.
- Conduct caregiving intervention studies, particularly those that involve clinical trials, those that focus on targeting interventions, and those that consider program evaluation as part of the outcome variables being studied.
- Examine the consequences of caregiving for the caregiver using a combination of physiological and psychosocial methods.
- Evaluate the positive consequences of caregiving and methods for fostering growth through the caregiving experience.
- Investigate the relationship between the health care system (and changes in the health care system) and the processes and outcomes of caregiving.
- Describe the ethical dilemmas associated with family caregiving.
- Describe the processes and outcomes of caregiving and the consequences of caregiving for the elder from the elder's perspective.

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