

SUPPORT SYSTEMS OF AFRICAN-AMERICAN FAMILY CAREGIVERS OF ELDERS
WITH DEMENTING ILLNESSES

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ABSTRACT

Researchers of this pilot study examined the informal (unpaid) and formal (professional) help received by 47 urban African-American family caregivers of elders with dementing illnesses. Caregivers reported a mix of informal and formal help received. Of the five sources of help that caregivers received, family was the predominant source. Study results are discussed within a family ecology framework.

Dementing illnesses impair a person's cognitive functioning, with Alzheimer's disease being the most common dementing illness affecting approximately 4 million American adults and almost five times as many family caregivers (Gwyther, 1995). Current growth in the elderly population and an increase in their longevity suggest a trend toward an increasing number of elders with demented illness. When one considers this trend along with a low nursing home placement rate for chronically ill African-American elders (Morrow Howell & Proctor, 1994), there is justification for researchers to carefully assess the informal and formal support systems available to African-American family caregivers. Based on a literature review of African-American caregivers of chronically ill elders, Hines-Martin (1992) has concluded that "the depth of information about the African-American caregiver is strikingly lacking" (p. 28). She has further identified the caregiver's use of informal and formal supports as an area deserving further study.

This pilot study of 47 African-American caregivers sought to better understand the informal and formal support systems of caregivers of elders with dementing illnesses. Research questions guiding this study were: 1) What type and frequency of help is reported by caregivers? 2) How close do caregivers report they feel to helpers? 3) How frequent do caregivers report helpers as criticizing caregivers' performance? 4) How frequent are caregivers in contact with helpers? Results of this study were deemed important especially for the local Alzheimer's Association in targeting family services for African-American caregivers of elders with dementing illness, who underused this agency's caregiver support services.

Informal family caregiving in this study includes giving aid or assistance beyond ordinary daily tasks to an older person with a dementing illness (Walker, Pratt, Clara & Eddy, 1995). It differs from formal aid or assistance which is typically performed by a paid, professionally-skilled helper. Some tasks performed and type of aid or assistance rendered by caregivers to elders may overlap for family and professional caregivers, particularly when the elder is chronically ill (Walker et al, 1995).

Overview of the Literature

Evidence from a national survey indicates older African-Americans are imbedded within a supportive informal network composed of extended kin and non-kin (Taylor & Chatters, 1991; Chatters, Taylor & Jackson, 1985). Research suggests the informal kin network available to African-American elderly may be a source of assistance to their caregivers. Scholars report that African-American caregivers of elderly persons with dementia receive both tangible and psychological help from family members (Cox & Monk, 1990; Wood & Parham, 1990).

The church is also an important source of support to older African-Americans (Gibson, 1982; Heisel & Faulkner, 1982; Taylor & Chatters, 1986) as well as their caregivers. Segall and Wykle (1988-89) found that African-American caregivers of elders with dementia identified prayer, religion and faith in God as the predominant way of coping with caregiving. Correspondingly, Wood and Parham (1990) reported that African-American caregivers of elders with dementia considered God an important member of their informal support system, providing them with strength to carry out caregiving responsibilities.

Caregivers also receive support through the formal service system. In a recent review of the caregiving literature on service use, Cox (1993) concluded that African-American caregivers underuse formal services. Caregivers low use of formal services may not mean an absence of need for formal assistance. Cox (1993), for example, found African-American caregivers of elders with dementia tended to underuse services, even though they expressed need for more services.

Family caregiving has been typically framed within a stress and coping (Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991; Pearlin & Zarit, 1993) or a biomedical paradigm (Lyman, 1989). But Lyman (1989) has claimed that such paradigms neglect caregivers' relationships with the larger environment. This study used a family ecology perspective that views families and individuals as interacting with multiple environments. According to this perspective, the environment is an important source of tangible and psychological support for families and family members (Bubolz and Sontag, 1993; Westney, 1993). This perspective further views environmental resources in addition to individual and family attributes as critical factors in helping sustain individual and family quality of life.

METHODS

Study Design

Caregivers in this study were a convenient urban sample of 50 residents in a midwestern metropolitan area. A caregiver was eligible for study participation if 1) a physician had told them the elderly person had Alzheimer's disease or a related disorder (e.g., Parkinson's disease, multi-infarct dementia), showed clinical symptoms of severe memory loss and confusion, and the elder being cared for (care recipient) was living in the community. Most caregivers reported Alzheimer's disease told by a physician (n=39), with the rest who reported dementia from Parkinson's disease (n=3), multi-infarct dementia (n=1), and symptoms of severe memory loss and confusion (n=7). Three caregivers were dropped from this study's analysis because elders had been institutionalized at time of interview.

Regarding recruitment, 15 caregivers self-referred through a study number listed in a local Black newspaper. The local Alzheimer's Association referred 11 caregivers who called its Caregivers' Hotline. The remainder of the caregivers were referred through a local community agency (n=6), an area agency on aging (n=2), a church support group (n=7), adult daycare newsletter (n=5) and a local health agency (n=4). In situations involving an agency, oral consent was gained from the caregiver before making a referral. Study staff screened caregivers to certify their eligibility. Interviewers obtained written consent from caregivers to participate in the study at interview.

Data Collection

Information about caregivers' informal and formal help received was obtained through a survey interview, conducted between June, 1992 and May, 1993. Study staff pretested interviews one month prior to interviewing. Three African-American women graduate students were trained to conduct in-home interviews with caregivers, who were reimbursed \$10 for study participation. Interviews average about 60 minutes.

Measures

Caregivers' informal and formal support was assessed using a modified social network map and grid developed by Tracy and Whittaker (see Tracy, 1990). Five sources of help were assessed: help from other *family members, friends or neighbors, people from work, people from church, and agencies*. Caregivers were asked how frequently ("hardly ever or never," "sometimes," or "almost always") they could rely on each source for *Concrete help* (e.g., help with household duties, shopping, getting to the doctor), *Emotional help* (e.g., comfort, be there when times get hard, listen to caregiver talk about feelings), or *Information and advice* (e.g., give information and help caregiver make a big decision). Caregivers were further asked how frequent helpers criticized caregivers' performance (e.g., make caregivers feel they are not doing a good job in their caregiving role): "hardly ever or never," "sometimes," or "almost always." *Closeness to helper* was assessed by asking caregivers how close they felt to each helper: "not very close," "somewhat close," and "very close." Caregivers reported how often they had *Contact with helper* by responding "hardly ever or never," "few times a year," "at least once a month," "at least once a week," or "nearly every day."

The researchers assessed the care *recipient's physical functioning* by asking the caregiver the extent to which the elder required assistance with three activities in daily living: feeding, dressing, and toileting ("without assistance=0," "with minor assistance=1," "with much assistance=2," "unable to perform an activity=3"). They constructed a measure of the care recipient's physical functioning by summing the values over the three activities, with higher scores indicating lower levels of physical functioning. Regarding the care *recipient's cognitive functioning*, caregivers responded "all ability=2," "some ability=1," or "no ability=0" to seven items in the Blessed Dementia Scale: ability to perform household tasks; cope with small sums of money; remember a short list of items; find way about indoors; find way around familiar streets; grasp situations or explanations, and recall events (Blessed, Tomlinson & Roth, 1968). Caregivers were asked a seventh item about how frequently the demented person dwelled in the past: "none of the time=0," "sometimes=1," or "frequently=2." The seven

items were summed to form the Blessed Dementia Scale with possible scores ranging from 0 to 14; lower scores on this scale indicate greater cognitive impairment.

SAMPLE PROFILE

Of the 47 caregivers included in these analyses, almost one-half (47 percent) were married, one third (34 percent) were divorced or separated, and the remainder were widowed (6 percent) or never married (14 percent). Caregivers averaged 57 years of age (range=30-80 years; SD=14.02) and 58 months of caregiving (range=4-168 months; SD=40.44). On average, caregivers had 13 years of schooling (range=5-17 years; SD=2.75). Their annual household incomes averaged between \$17,000 and \$19,999. Almost one-half of the caregivers were unemployed; about one-third were working full or part-time; one-fifth were retired. Caregivers were primarily women (77 percent). With regard to the relationship of caregiver to care recipient, caregivers were mainly daughters (39 percent) and spouses (23 percent). Sons, siblings, nieces, grandchildren, and other relatives in the order given constituted more than one-third of the caregiving sample. Most caregivers lived with the care recipient (83 percent). Regarding religious denomination, most caregivers reported Baptist (66 percent) or Catholic (26 percent).

FINDINGS

Caregivers reported providing assistance to mainly older adult women (83 percent), widowed (50 percent) or married (40 percent) elders. Care recipients' average age was 78 years (range=60-89 years; SD=6.24). Reports from caregivers about care recipients' cognitive functioning yielded an average score of 3.5 (range=0-14, SD=3.0) on the Blessed Dementia Scale, indicating poor cognitive functioning. Caregivers' assessment over three activities in daily living for the care recipients yielded an average score of 4.1 (range=0-9, SD=3.1), indicating moderate physical functioning.

Of five different sources of help that we asked caregivers about, family help was the most frequent (Table 1). Thirty-eight of the 47 caregivers reported they could count on family for help.

Help from people at work was least frequent, with only a small number of reports (n=4) about co-workers. Thus, these reports were not included in study analyses. Caregivers reported professional help (n=34) as the second most frequent source of help received, friends and neighbors (n=23) as the third most frequent source of help received, and church people (n=19) as the fourth most frequent source of help.

The type of assistance received by caregivers varied with the source of assistance (see Table 1). Seventy percent of caregivers who reported family help said they could count on family helpers sometimes or almost always for concrete; 78 percent reported they could count on family helpers sometimes or almost always for emotional help (78 percent); 62 percent reported they could count on family helpers sometimes or almost always for informational help.

Emotional help was the most frequent type of help received from family, friends and neighbors, church people and professionals. At least 60 percent of caregivers reporting friends and neighbors help and more than 70 percent of caregivers reporting church people help could count on these helpers sometimes or almost always for emotional help. Information and advice was the second most frequent type of assistance that caregivers received. Among caregivers reporting professional assistance, 61 percent could count on these helpers sometimes or almost always for information and advice.

A high percentage of caregivers (90 percent) reporting assistance from family, friends and neighbors expressed feeling somewhat or very close to these helpers. A somewhat lower although still high percentage of caregivers reporting church and professional help expressed feeling somewhat or very close to these helpers (70 percent). However, among caregivers reporting church and professional help, slightly more than one-quarter expressed feeling not very close to these helpers.

Many caregivers who reported they could count on friends and neighbors, church people, and professionals for help perceived these helpers as hardly ever or never criticizing caregivers'

performance (90 percent). On the other hand, almost one-quarter (23.7 percent) of caregivers reporting they could count on family help perceived these helpers as sometimes or almost always criticizing caregivers' performance. Thus, among the different sources of help, caregivers perceived family members more often than any other helpers as criticizing caregivers.

Caregivers expressed feeling closest to and having the most contact with family, friends and neighbors: 68 percent of those reporting family help and 56 percent of those reporting friends and neighbors help were in contact almost daily with these helpers. These percentages contrast with those for caregivers responding church and professional help: 15 percent responding church help and none responding professional help reported almost daily contact with church people and professionals respectively.

--Table 1 about here--

DISCUSSION

Certain findings in this pilot study confirm and add to current knowledge about the informal and formal support available to African-American caregivers of elders with dementing illnesses. With regard to the types of help received, caregivers report three types-- concrete help with household tasks, shopping, and transferring the elder; emotional help as comfort, listening, and having someone to standby during hard times; information and advice as receiving information and help with making a big decision.

Although caregivers report some amount of help received from five different sources (family, friends and neighbors, people at work, professionals and agencies), this study finds that family members are a pivotal force in caregivers' support network. This finding is consistent with prior research (Chatters, Taylor & Jackson, 1985; Cox & Monk, 1990; Lawton et al, 1992; Mindel & Wright, 1982; Mui, 1994; Taylor & Chatters, 1991; Wood & Parham, 1990). The role of family members is evidenced in four way-- the high number of caregivers who report family as a source of

help, who report feeling very close to family helpers, receive all three types of help from family, and have almost daily contact with family members. A caveat about these findings: policy makers and service providers must not mistake them to mean that caregivers have low need for formal services (see Cox, 1993). Caregivers assess elders as having high cognitive impairment and moderate physical functioning, and this raises some concern about the level of care needed for elders.

The availability of and frequent contact with family members in this study may signal a mixed blessing for caregivers. Caregivers also report family members more than any other group of helpers as expressing disapproval (e.g., making caregivers feel they are not doing a good job) about caregivers' performance. Prior research has devoted attention to primarily positive aspects of the caregiver's support network. This study's finding about criticism from family members about caregivers' performance help clarify possible negative aspects in the relationships of caregivers with other people in the social environmental context. Identifying the source of criticisms in caregivers' relationships with other people is important, as research suggests that negative factors in a person's social support system may possibly threaten supportive relationships (Fiore, Becker & Coppel, 1983).

Caregivers report both informal and formal help received. This finding dovetails with results reported by Mindel and Wright (1982), who find that African-American elders are the recipients of family and outside sources of formal supports. Study findings about the informal and formal help received add to current knowledge by better clarifying the role played by informal and formal helpers in caregivers' support network. The help received by caregivers from professionals and agencies with elders appears to supplement family assistance. Professionals and agencies play a prominent role in assisting caregivers with concrete support as well informational support. Study findings about caregivers' use of both informal and formal help are also consistent with a family ecology perspective that views individuals in families as interacting with multiple environments. Despite caregivers' reports of infrequent contact with formal helpers relative to informal helpers, many caregivers express

feeling close to professional and agency helpers. Caregivers' affective ties to outside helpers are consistent with the notion of family ecology theory that views family members as having relationships with people in other environments.

Women are the predominant gender group among caregivers to older relatives with dementing illnesses in the current study. This finding suggests that gender may also shape the supply and demand of family assistance to caregivers of older African-American, as scholars suggest (Abel, 1991; Brody, 1990). Congruent with prior research on African-American family caregivers' (Hinrichsen & Ramirez, 1992; Lawton et al, 1992), current findings indicate caregivers are more varied in terms of their relationship to elders. Over one-third of caregivers were sons, siblings, grandchildren, and nieces.

Friends and neighbors as well as church people also assist caregivers by providing mainly emotional support. This finding further elucidates the broad range of people with whom caregivers interact in the larger informal environmental context. Study findings about the role of church people dovetails with prior research suggesting that African-American caregivers of elders with dementia report religion and the church as mainly a provider of psychological support (Segall & Wykle, 1988-89; Wood & Parham, 1990).

Certain limitations are noted in this exploratory pilot study, thus limiting generalizability. These include type and size of sample as well as the recruitment strategy for participants. Caregivers were a convenient urban sample of 47 caregivers, some of whom were recruited through agencies. Future research is needed to overcome these limitations.

Additional research is needed to replicate the findings of this study with larger samples of African-American caregivers in different environmental contexts (e.g., rural vs. urban). Efforts to better understand caregiving within a family ecology perspective--a dynamic system involving families

in nurturing and supportive relationships with the social environment--should also be extended to future research.

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