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ASSESSING FIT BETWEEN INFORMAL AND FORMAL SUPPORT FOR DEPENDENT ELDERLY: HOW FAMILIES HAVE MANAGED ELDER-CARE IN NORTH DAKOTA

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The North Dakota Eldercare Study was conducted to provide specialized data on caregivers (i.e., a spouse or an adult child) and their dependent elderly relatives based on a probability sample of rural communities throughout the State of North Dakota. Based on the study's data, this paper will document (1) the availability and utilization of health and social services and (2) family caregivers as a resource in the care of elderly relatives. This paper will also discuss how useful the formal service delivery system is in meeting the needs of family members.

Regional and national studies document how families help their elderly members contend with the challenges of daily living to keep them in their homes and out of hospitals and nursing homes (see Seltzer, Ivry, & Litchfield, 1987; Stone, Cafferata, & Sangl, 1987; Johnson & Catalano, 1983; and Litwak, 1985). For most families, elder-care involves *balancing* informal patterns of care with the use of formal community-based services and *coping* with the unpredictable nature of physical and mental illnesses. The family, social, and community support systems which accompany such commitment are now well-documented in geriatric and gerontological research on urban samples. To date, however, the rural elderly and their caregivers have not received the same attention as their urban counterparts. One result of not differentiating caregiving situations by residential location has been to obscure important differences among primary caregivers, care recipients, and their caregiving networks. These differences have

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state were made during the Summer of 1990. Over an eight week period, a random digit dialing procedure produced 110 households eligible for study participation. Of this number, 57 caregivers completed the survey resulting in a 52 percent response rate. Interviews ranged from 25 to 40 minutes.

To describe and measure the configuration of elder-care adopted by families, the study's semi-structured questionnaire had the following components: (1) a sociodemographic and situational profile of the caregiver and his/her dependent family member at the time of the study; (2) a profile of the caregiver when some form of assistance was initially required and (3) a profile of the caregiver at the time of the study, including the type, frequency, length of time, and number of formal and informal services used to provide care. The questionnaire elicited information about the care provider related to the perception and performance of caregiving at two points in time. The format, therefore, used parallel sets of questions.

Characteristics of the sample

Table 1 provides a sociodemographic profile of North Dakota care providers and their dependent family members. The age of the caregivers ranged from 26 to 74 years with a mean age of 54 years. About half were between 40 and 59 years of age. The care recipients' ages ranged from 62 to 97 years with a mean age of 80 years. As would be expected from previous research in this area (Stone, Cafferata, & Sangl, 1987), the majority of caregivers and care recipients were female. Over three-quarters of the caregivers were married and cared for widowed relatives. The remaining care recipients were either married or divorced. One-third of the caregivers worked full-time while a similar number were retired at the time of data collection.

In terms of care provider-recipient family ties, less than one-fifth of this sample were spousal caregivers. Of this group, all provided care for their husbands. About two-thirds were care providers for their mothers or mothers-in-law. The remaining ties were associated with fathers, fathers-in-law, and one brother. The length of time as a caregiver ranged from "5 months" to "99 months

or greater." Over one-third of the study's caregivers reported their status had lasted "99 months or greater." Most of those sampled, therefore, provided some form of care for at least 8 years.

Over two-thirds of the families in this study lived in towns or cities defined by the U.S. Bureau of the Census as rural (i.e., a place having less than 2,500 persons). Of this group, the average number of residents was 675 with a range of 49 to 2,241. Just under sixteen

Table 1. A Sociodemographic Profile of North Dakotan Caregivers and Their Care Recipients

Variables	Caregivers (n = 57) Percent	Frq.	Care Recipients (n = 57) Percent	Frq.
Female	86.0	49	66.7	38
Married	77.2	44	29.8	17
70 years or older	14.0	08	80.7	46
Completed high school	29.8	17	22.8	13
Family income $15,000 or less	30.0	15[1]	81.2	26[2]
Living in a rural town or city of 2,499 or less	68.4	39		
Providing elder-care for 9 years or more	38.6	22		
White	98.2	56		
Working full-time	33.3	19		
With mother as care recipient	49.1	28		
Ethnicity either German or Norwegian	68.4	39		

[1]Calculated based on 50 caregivers due to missing income data.
[2]Calculated based on 32 care recipients due to missing income data.

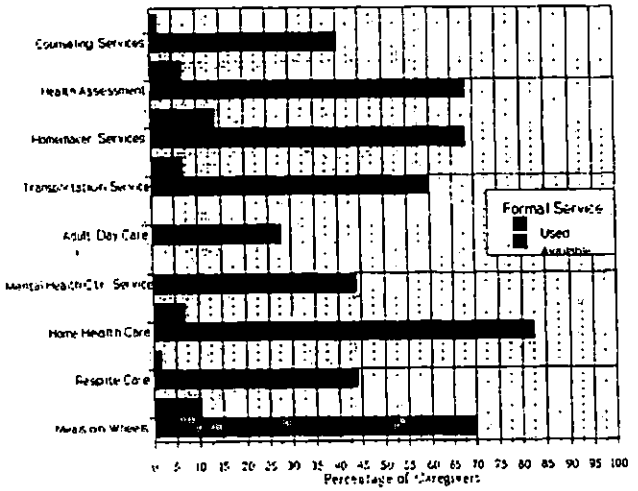
percent lived in cities having 20,000 or more inhabitants. The average number of residents in this group was 39,463 with a range of 34,544 to 49,425.

HOW NORTH DAKOTAN FAMILIES MANAGE ELDER-CARE

The context in which elder-care is provided to meet the needs of dependent family members and to identify potential areas of unmet need connected with such care is critical. Conventionally, this context has been divided into two areas: formal care provided by way

of community-based organizations and informal care provided by family members, friends, or other people who comprise a family's social network.

Table 2. Percentage of Caregivers Reporting Availability and Use of Formal Services



Studies on the type, number, and relative use of formal community-based services reveal that there are up to nine formal services potentially available to families providing elder-care (Horowitz, 1985; Stone, Cafferata, & Sangl, 1987; and Ziner, 1986). They are Meals on Wheels, respite care, home health care, community mental health centers, adult day care, transportation, health assessment and maintenance, homemaker, and counseling services. Table 2 shows the percentage of caregivers reporting the availability and use of each of these formal services in their

communities. Since the needs of the dependent elderly and their family members are complex, what is relevant here is how many of these services are available to families, how many families actually use these services, and whether or not any needs are unmet by formal service organizations.

It is clear that most North Dakotan families have a range of formal services from which to choose. The extent to which these services are reported by respondents to be available, however, would seem to contradict studies that have found the availability of such services to be typically diminished in rural areas (Coward & Rathbone-McCuan, 1985; Krout, 1986). Conversely, the percentage of formal service use also shown in Table 2 does support reports that rural families have low utilization rates (Krout, 1983). The majority (52.6 percent) of caregivers in this study reported no formal service use in the course of elder-care. Although this is consistent with previous research, it appears that the reason behind such low service use by North Dakotan families differs from prior studies. It has been contended that limited financial resources in rural communities and the low residential density of its residents limit the availability of many formal services that are often used by families in urban communities (Coward & Lee, 1985; Nelson, 1983). Limited services mean fewer options for assistance and, hence, lower utilization rates in rural areas. This explanation does not seem to fit the experiences of families in North Dakota. As Table 2 reveals, it is clear that while a range of formal services were available, most families either could not or would not use them. Even in the families that have cared for an elder for more than eight years, nearly 70 percent did not use any formal agency.

Part of the explanation for the non-use of formal services may be found in the culture of rural communities. Conservative by nature, members of these communities are likely to resist efforts of formal agencies or "outsiders" to address what are perceived as family problems. This perception is consistent with Krout's (1983) research on the rural elderly. He contends that low service use may be a product of the negative attitudes the rural elderly share toward formal service organizations. Another reason may stem from a perceived stigma connected with using certain services, per se, such

as counseling and respite care. Unlike metropolitan areas, rural communities are places where people usually know one another's business well. Places where people tend to know about others' problems and support one another informally as a result. Similarities in many social characteristics including ethnicity, religion and group affiliations and the frequency of contact associated with maintaining these ties, foster such knowledge and support.

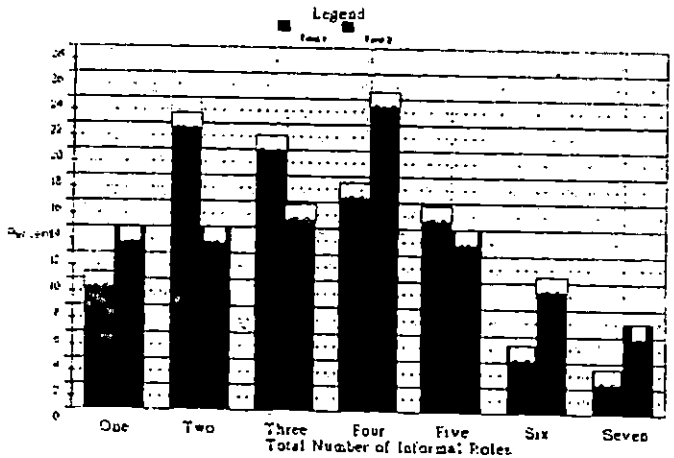
To shed more light on low formal service use, two additional questions were examined in this study. Are low utilization rates a function of the frail elderly being offered services which they do not need? That is, are the wrong services present in their communities? Approximately two-thirds of the sample (67 percent) reported that five or more services were available and only a small minority (8.8 percent) reported that no formal services were present. This means that not only was *any one* service likely to be available to assist with elder-care (see Table 2), but that a combination of services (mode = 6) was the rule rather than the exception in most rural communities.

There is, however, the potential for an unmet need to slip through the cracks of the formal service system in a community. In this context, the second question is whether or not any formal services were "needed and unavailable." This issue is crucial not only to inform area agencies on aging of potential service gaps, but also to obtain information on the special problems of the rural elderly and their families. Caregivers reported that no formal services were needed that weren't already available in their communities. This finding supports prior research which contends that the rural elderly rely mainly on their family, friends and other members of their informal networks to meet their daily needs (Blieszner, McCauley, Newhouse & Mancini, 1987). In what ways, then, do rural caregivers assist their dependent family members?

Studies on the type, number, and relative use of informal services provided to the dependent elderly reveal that up to seven caregiving roles may be performed at any one time (Horowitz, 1985; Litwak, 1985; Stone, Cafferata, and Sangl, 1987; and Ziner, 1986). They are household assistance, personal care and grooming, transportation, medical attention and assistance, meal preparation,

financial management, and mobility assistance. Table 3 shows how the total number of informal caregiving roles have changed over time and that sizable changes are evident. At the outset of care, the mean number of informal roles was 3.3 with a mode of two. By the time of the study, the mean number of informal roles had increased to 3.8 and a mode of four. As anticipated, for both time frames the total number of informal roles increased as the care

Table 3. Percentage of Caregivers Providing Informal Roles by Total Number Over Time

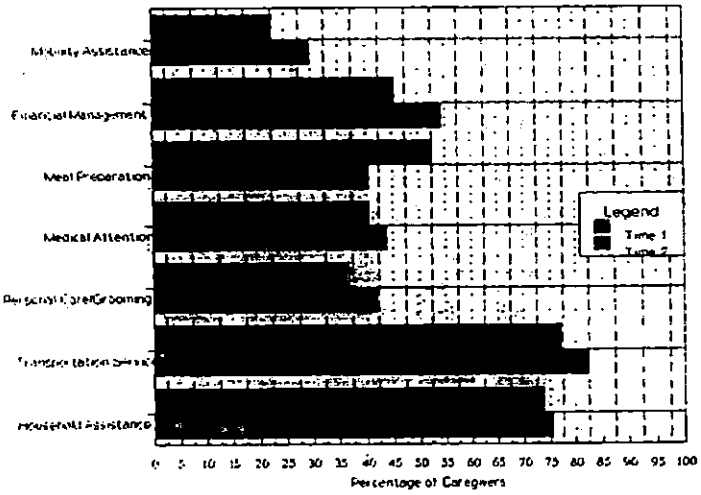


recipients' physical health status decreased. This finding is consistent with research conducted on urban caregivers which demonstrates that the number of informal roles tends to increase over time (Ziner, 1986).

Table 4 addresses how the caregivers' level of involvement in any one informal role changed from the onset of care to the time of the study. In all areas except one the percentage of informal services provided by caregivers increased over time. The only informal role to decrease over time was meal preparation (-12.2

percent). One explanation for this may be found by comparing informal care with formal service use in this area. Over time, the drop in the percentage of caregivers' preparing meals was associated with an increase in the percentage of elders enrolled in the senior

Table 4. Percentage of Caregivers Providing a Specific Informal Role Over Time



meals program. Again, a comparison of informal and formal services may help to explain why this has occurred.

The formal service most widely used by families was homemaker services. This form of aid does not require direct contact with the elderly and may even be perceived as "help in cleaning up around the house." Like Meals on Wheels, the decision to use homemaker services needs to be viewed in a rura

context. Research has shown that the rural elderly hold negative views toward using formal agencies to perform the tasks that family members can and should do (Krout, 1983). With the strong social networks that often are a part of rural communities, people are more likely to turn first to family and then friends for needed assistance. Since the number of people in most North Dakotan communities are typically very small, Meals on Wheels and homemaker services are likely to be delivered by people known and trusted by the family. In these circumstances, agency representatives are extensions of their informal networks, rather than "outsiders."

Caregivers provided information on the level of social support received from their informal networks. It appears that most caregivers felt there was a "great deal of support" from family, friends, neighbors, and their local church when their caregiving efforts began. But by the time of this study, a decline in support from spouses was reported. This shift was to the "moderate support" category. In no other area measuring support was a significant change found. Perhaps this loss of support is due to the challenges of providing care in rural and frontier communities. Access to and availability of a grocery store, doctor, bank, or church is more limited than in urban areas. Providing access to these and other "area" services may require several hours of time and coordination with family and friends. In the harsh winter climate of North Dakota, this situation is compounded. Further, under the normal circumstances of providing care to a dependent loved one, there are many tasks required of family members that are ongoing. Services range from bathing and dressing and changing clothes and linen to cleaning afflicted areas and changing bandages. In light of other responsibilities in the lives of caregivers, even the most devoted spouse or adult child and their families will likely feel its effects over time.

Finally, this study assessed the effects of support from caregiver spouses, children, and neighbors *on* the number of informal roles. With a decrease in the level of spousal support over time, the total number of informal roles performed by caregivers tended to increase. Conversely, with an increase in the level of support from adult children and neighbors over time, the total

number of informal roles performed by caregivers tended to decrease. In this context, the importance of building and sustaining social networks to manage the long-term care needs of a dependent family member was suggested.

IMPLICATIONS

Nationally, policy changes in the financing and delivery of health care services to the elderly have reduced the amount of resources available to communities for elder-care. As the budgets of service agencies have decreased nationwide, the result has been to place greater pressure on informal networks to manage the needs of dependent family members. Despite this major health policy transition, this study shows that communities throughout North Dakota make available a large number of formal services for the dependent elderly. Yet, few families actually use these services. These findings may point state policy-makers in a new direction.

Rather than considering as primary the formal service delivery system for maintaining the elderly in their communities, I suggest that closer attention be paid to informal caregivers and the complex roles associated with *their* activities of daily living. Nationally, studies on elder-care have for decades shown that the vast majority of care is provided informally by family members (Shanas, 1979; Horowitz, 1985; Stone, Cafferata, and Sangl, 1987; and Dwyer & Miller, 1990) and that the major cause of unnecessary institutional placement is not the physical or mental decline of the care recipient, nor the depletion of the family's financial resources, but the demands placed on family members who can no longer provide care for their loved ones without undue risk to themselves or to the well-being of other family members. The focus in the future, then, should be to examine informal caregivers in the state.

By analyzing the balance of informal roles and formal services used by rural caregivers to provide elder-care, patterns may emerge -- patterns which contribute most to caregiver stress and burden (Zinet, 1986): a complex, yet measurable, personal and social problem. Caregivers do not want to be replaced; they want to be helped in specific ways. By targeting family members who are "at risk" of such stress due to their caregiving configuration, the formal

service community may be able to supplement or even supplant entirely a particular form of needed care. Given that rural North Dakotans do not seem to want to be helped, outreach efforts would also be needed to educate caregivers and their families about the important supportive roles formal agencies can play in their community. This may result in public and private agencies providing a better fit between the services they offer and those families will use. To help them, we must first determine the services that they need, and then provide those they can and will use. Such a process may result in a reduction in caregiver burnout due to a more manageable long-term care relationship. It may also result in savings at the local and state levels. One final way to help would be to examine closely the two services, Meals on Wheels and homemaker services, that families do use. Why do these programs work while others do not? Maybe it is because it they are run by members of the community that families often know personally. Ultimately, these steps should lead us to an important goal -- to design programs that help caregivers (mainly women) take care of their loved ones and, at the same time, minimize stress, physical costs and the loss of family and community support.

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