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Caregiving as a Process of Changing Identity:
Implications for Caregiver Support

How to assess caregivers' various and individual sources of distress in order to fully support them in their journey.

Informal caregivers serve as the primary instrument of long-term care for people with dementia and other chronic conditions in American society. Not surprisingly, then, providing support to caregivers has become an important practice and policy issue.

The great variability among caregivers in the experience of caregiving suggests that caregiving is an idiosyncratic process, a conclusion that has several important implications. First, any caregiving situation is, always and necessarily, a unique situation. Thus, there is no such thing as an "average" caregiver.

Second, there are great differences among caregivers in the pressure they feel to take on the caregiving role in the first place, in their expectations concerning the duties they are obligated to perform, and in the circumstances that allow them ultimately to relinquish the role. These differences simply reflect the unique histories and circumstances that accrue to individuals situated in a specific family, in a specific culture, at a particular historical time. Thus, knowing how one caregiver experiences the role will tell us very little about how another caregiver, even one performing objectively similar care tasks, experiences the role.

Third, and most important, the caregiving role emerges from an existing role relationship. The caregiving role should not be seen as a new role that is added to one's repertoire of social roles but, rather, is most usefully viewed as the transformation of an existing role relationship. Indeed, for spouses, children, and even friends, this role relationship will almost certainly be one of the most meaningful social relationships in their lives. Overall, the extensive body of work on caregiver outcomes shows wide variations, not only in the tasks that caregivers undertake, but also in the costs they incur and the benefits they experience as a consequence of their caregiving role (Dilworth-Anderson, Williams, and Gibson, 2002; Haley et al., 1995) (see Fox and Max, this issue).

Effective Interventions to Support Caregivers

The effort to support informal caregivers has not been a straightforward matter, primarily because most efforts to intervene have not addressed the variability in the caregiving experience. The types of services that have been most frequently examined include educational programs, counseling, support groups, and respite

services delivered in various formats (Schulz et al., 2002; Sorensen, Pinquart, Duberstein, 2002).

The most promising findings regarding the positive impact of support services have emerged from intervention studies that have included a relatively comprehensive set of support services such as the randomized, controlled trial of multicomponent interventions (e.g., Bourgeois, Schulz, and Burgio, 1996; Burgio et al., 2003).

While much has been accomplished to support caregivers, it should also be noted that many caregivers decline to use services that, ostensibly, would be helpful to them (Kosloski, Montgomery and Youngbauer, 1999). Indeed, a common complaint among service providers is that informal caregivers use services in a manner that can only be described as "too little, too late." Moreover, among those who begin to use a service such as respite, fully one-third discontinue it within the first ninety days. For these individuals, it is hard to escape the inference that the service was simply not what the caregivers needed at that time (Montgomery et al., 2002).

A major problem is that most programs designed to intervene and support caregivers have overlooked the importance of the longitudinal and dynamic nature of caregiving. Effective interventions must recognize (a) the diversity among caregivers, (b) the significant changes in the caregiving context that occur over the caregiving career, and (c) the corresponding changes that define the need for assistance.
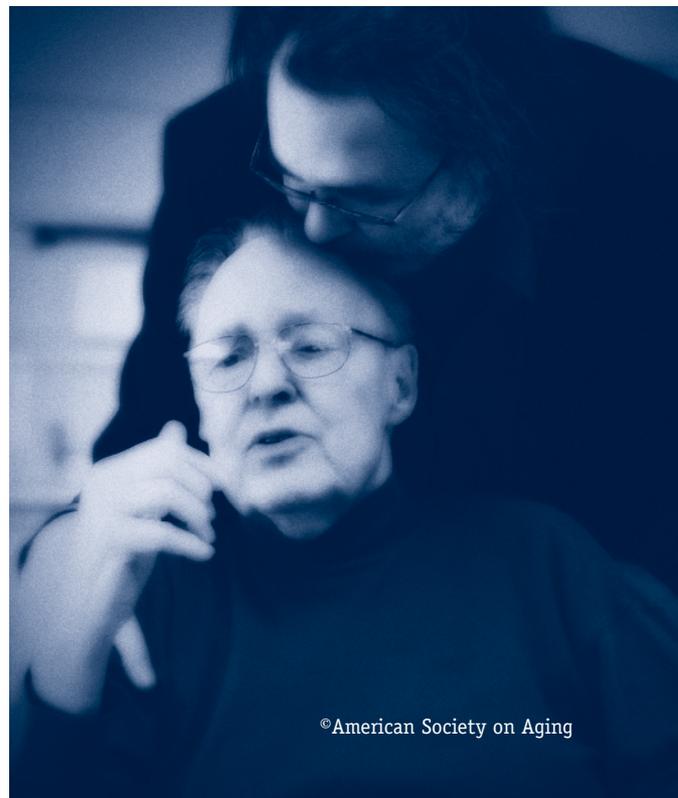
Caregiver Identity Theory

A recent approach to helping caregivers is based on the caregiver identity theory articulated by Montgomery and colleagues (Montgomery and Kosloski, in press; Montgomery, Rowe, and Kosloski, 2007). This approach views the caregiving career as a series of transitions that result from changes in the caregiving context (e.g., changing activity patterns, changes in the health of the care recipient).

According to the theory, the caregiving role emerges out of an existing role relationship, usually a familial role such as daughter, wife, or husband. Like many other social behaviors, caregiving is governed by norms or social rules. For example, the prominence of adult daughters and daughters-in-law in the caregiving role suggests that systematic cultural rules operate to dictate responsibility for care. In addition, a person's ethnic and cultural background influences her expectations because each culture has its own norms relating to caregiving responsibility (e.g., Connell and Gibson, 1997; Haley et al., 1995). To complicate matters further, each family develops its own unique family ethos (e.g., Brubaker and Brubaker, 1989; Pyke and Bengtson, 1996). This ethos actually determines which members in the family are responsible for caregiving, the types of care that can be expected, and the conditions under which it might be appropriate to seek help from outside the family— from formal service providers, for example. The caregiver brings this initial relationship with the care recipient to the caregiving situation, along with an idiosyncratic set of beliefs and expectations about his or her duty to provide care.

Over time, as the needs of the care recipient increase in quantity and intensity, a change takes

place in the relationship between the caregiver and the care recipient. Caregivers not only change their behaviors, but they also change the way they see their role in relation to the care recipient—that is, their role identity. This identity change occurs because the care tasks that are required to maintain the health of the care recipient become inconsistent with the expectations associated with the caregiver's initial role in relation to the care recipient. To a large degree, this shift in identity is necessitated by significant changes in the care context, which most often involves an increase in the level of dependency of the care recipient. Other signifi-

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cant changes in the care context, however, might include an increase or decrease in the availability of informal or formal supports, or a change in participants' living arrangements.

For most caregivers of people with dementia, any change in the role identity of the caregiver is likely to be a slow, insidious process that proceeds in stops and starts in response to changes in the caregiving situation. Initially, the care needs of the elder may be relatively small, and the corresponding care tasks may represent very small changes in the original role relationship. For example, consider a son who is providing some support for his 80-year-old mother who has an incipient dementia. He may begin by assisting his mother with such things as paying bills, shopping, or driving her to appointments. He is able to accommodate these caregiving activities into his lifestyle without undue distress. As her dementia advances, however, her needs for care, and the resultant demands placed on him as a caregiver, increase. As a result of these changes in the caregiving circumstance, his activities are now at odds with the expectations that he brought with him into the caregiv-

ing situation initially. That is, he now finds himself engaging in activities with respect to his mother that he never engaged in previously and that do not conform to his previous role identity. Furthermore, these activities make time demands that limit his other role performances—as a spouse or a friend, for example. The end result is incongruence between the duties he is now assuming as a caregiver and the way that he views his filial responsibilities, that is, his role identity as a son.

To the extent that the son's behavior is not in accord with his current self-view, the son experiences distress (for example, the oft-referred to caregiver burden), and he is under increasing pressure to reconcile this discord. That is, the incongruence between the caregiving tasks and the meaning he attaches to these tasks causes distress and prompts actions to restore congruence to relieve this distress.

We believe that such relief ultimately requires an identity change. This identity change, however, is usually not a smooth, continuous process. Rather, it is a process that alternates between periods of relative stability, wherein a role identity is maintained through small adjustments in behavior or changes in perception, and periods when there are significant shifts in the caregiver's identity that are associated with the acceptance of new norms for behavior. In the case of the caregiving son, to achieve congruence between his caregiving activities and his identity as a son, he must come to view himself as someone for whom the new set of caregiving activities now constitutes appropriate behavior.

In situations where the caregiving context is stable, it is easy for an individual to steadily maintain a role identity in relation to the care recipient. As the caregiving context changes, however, and the caregiver is no longer able to "stretch" his or her identity to assimilate the

change in caregiving activities, then identity change is necessary to avoid distress. It is for this reason that two caregivers can be performing the very same activities, and for one caregiver, the activities are distressing, while for the other, they are not. The level of distress depends on the extent of incongruence between what the caregiver is doing and his or her current identity standard for behavior within the caregiving relationship.

The identity change process can be thought of as entailing five possible phases of accommodation (see Figure 1).

Phase one occurs when the caregiver begins to perform caregiving activities that have not been part of his or her familial or friendship role in the past. For example, a son may begin taking his mother shopping for groceries when her mild cognitive impairment makes it difficult for her to go on her own. Because her husband's dementia has progressed, a wife may take on financial tasks that heretofore have been part of his responsibilities in their marital division of labor.

Phase two occurs when the caregiver realizes that his or her caregiving activities are starting to extend beyond the scope of the initial family or friendship role. It is usually during this phase that the caregiver comes to view him- or herself as a caregiver. Phase three is reached when the needs of the care recipient require caregiving activities that substantially extend beyond the boundaries of the original friendship or familial role. In many cases, these activities involve assistance with personal grooming. For some caregivers, adult children, for example, and recipients, this type of care causes varying degrees of discomfort.

Phase three may require activities with which neither the caregiver nor the care recipient is comfortable and that cause the caregiver to leave the caregiving role—sometimes necessitating other changes like a move to a nursing home for the care recipient. For caregivers who persist, caregiving now accounts for a substantial part, say, 50 percent, of the role relationship.

As caregiving requirements increase, a further shift in identity is required (phase four), with caregiving coming to dominate the role relationship. And although the nursing home option is considered at every stage of the caregiving career, the option now is reconsidered more frequently.
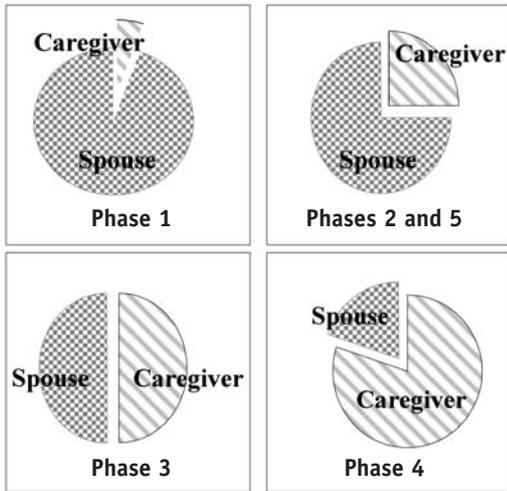
Finally, phase five is reached when the care recipient is moved to a different setting and the caregiver turns over the primary responsibility for care to formal care providers. Although informal caregiving does not end here, this new arrangement allows the informal caregiver to recover a substantial part of the original caregiving identity.

Although the five phases serve as a useful way of conceiving of the "typical" course of caregiving, it is important to note the great variability that exists in the trajectories of individual caregiving careers. Not every caregiver goes through every phase, and transitions are not necessarily unidirectional. The only uniform part of the transition process is that psychological distress precipitates movement between phases, and distress is relieved by the transition. As a result, burden or distress is not a linear function of time in the caregiving role. Instead, distress occurs whenever caregiving activities are perceived to be incongruent with one's current role identity.

Practice Implications

From the perspective of caregiver identity theory, reducing distress associated with caregiving is a straightforward matter: Reduce the incongruence between what the caregiver is doing—his caregiving activities—and what the caregiver thinks he should be doing—that is, his "identity standard." Although that task sounds a bit abstract, as a practical matter, there are only three avenues for reducing caregivers' identity incongruence: (1) change their behaviors to bring them into line with their identity standard, (2) change their self-appraisal or perception of congruence, and (3) change their identity

Figure 1
Changing Identity of a Caregiver
Possible Phases of Accommodation

Caregiver / Spouse — Phase 1

Caregiver / Spouse — Phases 2 and 5

Spouse / Caregiver — Phase 3

Spouse / Caregiver — Phase 4

efficient, or a respite program that gives her a greater opportunity to perform these household activities, would probably be more useful. The reason that many services go unused, are quickly discontinued, or fail to have their desired effect is that they do not address the true source of caregiving distress for a particular caregiver.

Changing self-appraisal

Another avenue for reducing the discrepancy between a caregiver's self-appraisal and his or her current identity standard is to change the self-appraisal. Usually this change is accomplished by helping caregivers cognitively reframe their perceptions of their behaviors. For example, consider a daughter who is told by her brother, who lives in another state, that she is not doing enough to assist their parent who has dementia. A support group, an education program, or individual counseling can all be useful ways for the daughter to reframe her assessment of her own behavior. A support group, for example, could help her to recognize that she is doing an adequate job.

Changing the identity standard

Another way to reduce the discrepancy between a caregiver's behavior and his identity standard for behavior is to modify the standard. This usually means adopting a new identity with a new set of rules that define the new identity. For example, through education or counseling, caregivers can be taught about the changing needs of the care recipient and shown how they can change their view of themselves or their identity by embracing a new identity that places greater emphasis on caregiving responsibilities than did their previous role relationship identity.

New Directions for Supporting Caregivers

The importance of effectively supporting family caregivers is great considering the breadth and variety of assistance that family members provide and the critical role that caregivers play as decision makers and gatekeepers who influ-

standard. When a specific support service is viewed as a mechanism for achieving one or more of these goals, the process of referring the caregiver to appropriate support services becomes more sensible. It also becomes clear that the commonly used "shotgun" approach of referring an individual to any number of services is not sensible and that a specific service can achieve more than one objective.

Changing behavior

An obvious way to bring a caregiver's behavior into line with her identity standard is to obtain outside assistance to perform those tasks that are incongruent with the behavioral standards of the initial familial or friendship role. For example, in-home chore services or home-delivered meals might serve this end. Consider, however, the plight of a wife who views household chores as an integral part of her existing identity standard. Abdicating these responsibilities is likely to actually increase the discrepancy between what she is doing and what she thinks she should be doing. For her, an education program that teaches her how to be more

ence the quality of care provided (see Fox and Max, this issue). Over the past three decades, an extensive body of work has emerged describing family caregivers and their context, identifying their need for support, and highlighting a wide range of intervention programs designed to meet these needs. However, the diversity of caregiving responsibilities and the dynamic nature of the caregiving experience require that more attention be given to assessing the specific needs and strengths of caregivers at a given time, identifying the sources of distress, and creating mechanisms to effectively target the sources of distress as well as the symptoms. Recent efforts that have been undertaken by scholars and advocacy groups underscore the necessity for effective caregiver

assessment (Feinberg, 2008). To fully support caregivers throughout their journey, we will need to (a) learn more about the specific sources of distress, (b) create clinically useful assessment protocols, and (c) design support programs that are sufficiently robust in terms of types of services provided and the flexibility for caregivers to use them in sufficient quantity at optimal times.

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