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INFORMATION FOR DECISION MAKERS

FOCUS ON: *Long-Term Care*

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INFORMAL CAREGIVER “BURNOUT”: PREDICTORS AND PREVENTION

There are approximately 4.6 million elderly Americans in need of long-term care who do not live in nursing homes. Over 90% of them rely--often exclusively--on family members and other informal caregivers for help with basic “activities of daily living” (ADLs) such as bathing, dressing, eating, etc. and “instrumental activities of daily living” such as cooking, shopping, and house cleaning. A main theme of policy-oriented research on informal eldercare has been understanding “caregiver burnout”-- why some family members choose to stop providing care. The aim is to identify interventions--such as increased access to paid helpers--that could sustain informal caregiving and prevent or postpone many nursing home placements.

Individual “Caregiver Burnout” Versus Exhaustion of the Informal Network’s Support Capabilities

Kasper as well as Boaz and Muller found that the decisions of individual caregivers of disabled elders to stop providing care were associated with decisions for nursing home placement in only 50% of cases. In the other 50% of cases the informal support network reconfigured and carried on.

Factors Associated with Individual Decisions to Quit

Boaz and Muller found the factors most significantly associated with individual caregivers’ decisions to quite to be the care recipients’ ADL limitations and the caregivers’ own “physical burden”. In particular, they singled out such burden indicators as frequent sleep interruptions and inability to leave the care recipient alone. Kasper found the caregiver’s appraisal of caregiving as more stressful than satisfying to be equally powerful in differentiating caregivers who quit. Spouse caregivers had significantly less propensity to quit than other relatives. Neither study found caregivers’ employment to be related to withdrawal from caregiving.

Predictors of Institutionalization Within Two Years

Kasper found the statistically significant predictors of a care recipient’s nursing home placement over a two year period to be cognitive impairment and advanced age. The caregiver’s appraisal of caregiving as “emotionally hard” also was a significant predictor. Miller and McFall identified three statistically significant care recipient characteristics associated with nursing home use within two years: advanced age, race (white), and high IADL impairment. In Miller and McFall’s research, cognitive impairment of care recipients was less strongly associated with placement than was caregivers’ level of “interpersonal burden”--as shown by their report that they “had a problem with” one or more care recipient behaviors (“forgetfulness”, “yelling”, “senile lapses”, and “embarrassing behavior”). Nursing home use was also predicted by higher levels of caregiver burden generally; i.e., by more problems of any sort--with emotions,

Factors Related to Ending Informal Care
<p>Why Individual Caregivers Quit</p> <ul style="list-style-type: none"> • Level of “Personal Burden” <ul style="list-style-type: none"> – Number of ADL Tasks – Unable to leave care recipient alone – Sleep disturbances • Stress Greater than Satisfaction • Other Helpers (Formal or Informal) Available
<p>Predictors of Nursing Home Placement Within Two Years</p> <ul style="list-style-type: none"> • Cognitive impairment • Advanced age (75+) • Race (white) • High IADL Impairment • High Caregiver Burden Scores <ul style="list-style-type: none"> – Especially “Interpersonal Burden” • Use of Formal Services

National Long-Term Care Survey Data

Three separate studies using the 1982 National Long-Term Care Survey (NLTC), its companion National Informal Caregivers Survey (NICS), and the longitudinal follow-up component of the 1984 NLTC analyzed decisions to terminate informal care among a nationally representative sample of disabled elderly and their family caregivers. The studies were sponsored by agencies of the U.S. Department of Health and Human Services--two by the Office of the Assistant Secretary for Planning and Evaluation (Miller and McFall 1989, Kasper et al. 1990) and one by the Agency for Health Care Policy and Research (Boaz and Muller 1991).

finances, time, health, etc.--that caregivers reported experiencing.

Use of Formal Services and Decisions to End Informal Caregiving

Surprisingly, Boaz and Muller found that caregivers were more likely to quit if care recipients also had paid help and/or there were other informal helpers. Caregivers without back-up help, either formal or informal--thought to be a greater risk of burnout--were least likely to quit. They may have felt more personally needed, perhaps indispensable.

Miller and McFall documented a statistically significant increase--from 19% to 27%--in the use rate of formal help over the two year study period among ADL-impaired elders who remained in the community and whose informal caregivers were close family members.

The care recipient characteristics associated with such increased use of formal care over time were increased ADL and cognitive impairment levels and deterioration in the reported health status of the disabled elderly care recipients. Formal helpers apparently served both to supplement informal care that was constant or increasing and to substitute for decreased availability of informal helpers. Male caregivers, youngest and oldest caregivers, and those who were more educated were more likely to use formal help.

Miller and McFall also found, however, that use of formal services in 1982 was a statistically significant predictor of nursing home use within two years.

Summary

The three studies confirm previous research linking high impairment levels, advanced age, and various indicators of caregivers' physical burden and emotional stress with individual caregivers' decisions to quit and increased likelihood of nursing home placement. In contrast, the

lack of association between caregivers' employment status and withdrawal from caregiving or decisions to institutionalize fails to support some widely held theories about the effects of female labor force participation on informal eldercare. Finally, the news is both good and bad about the impact of formal care. Informal care networks add paid helpers to cope with more intensive demands for assistance and/or losses in membership. Over time, however, formal services become less effective in preventing nursing home use.

What conclusions can be drawn? Formal services have thus far proved most useful in relieving the physical burden of caregiving. To do better at preventing individual caregivers from "burning out" as well as reducing nursing home placements, it will be necessary to develop better ways of helping caregivers manage emotional stress. Finally, since most caregivers appear to cope well with stress so long as they experience more satisfaction than stress, more research on the sources of caregiver satisfaction seems advisable.

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