An Approach to Health Care for Family Caregivers
- as partners in their own health care
- as managers of the care of older family members

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This multi-media program was developed in 1991-92 as an additional resource for use in Extension-sponsored training programs for unpaid family caregivers of the dependent elderly. The basic objective of the new resource is to increase the competency and effectiveness of the family caregiver of a dependent older adult in his/her own health care, and in the health care of the care receiver. This program proposes to reach its objective by helping these special health care consumers develop a better understanding of the personal health care process and their role and responsibilities as partners in that process. Consistent with that understanding, the program proposes to teach certain management, interpersonal and information-gathering skills that can help them become more effective health care partners.

Research Findings

Research included three original field studies of family caregivers as well as extensive literature review. The findings indicate multiple, extremely serious problems among older adults in regard to many aspects of older health care consumer decision making, especially in terms of medication management. These problems include inappropriate use of over-the-counter drugs (OTCs); polypharmacy; adverse drug reactions; non-compliance with medical advice (for a variety of reasons); and poor communication between health professionals and elderly patients.

"Lack of effective communication between older people and their health care provider was a major contributor to medicine misuse".....efforts must be undertaken to encourage consumers to work with their health care professionals and "to see themselves as partners in improving their health" (NCPIE Report 1987).

The average home of older adults has 17 OTCs (Coons 1988), yet only 12.3% had talked with a pharmacist about their use of OTCs in the past six months (Smith and Sharpe 1984). The magnitude of OTC selection -- and the potential for misuse -- is overwhelming, with over 300,000 OTC products on the market representing various combinations of 725 approved active ingredients. It is estimated that more than 200 of today's OTC products were unavailable except by prescription in 1976 (Coons 1988).

The incidence of multiple prescription and non-prescription drug use (polypharmacy) is greatest among older adults. Over 60% of all visits to a doctor by older adults include a prescription for medicine (Beers and Ouslander 1989). Polypharmacy is demonstrably a major factor in the large number of adverse drug reactions (ADRs) among older adults. In 1989, 243,000 persons required hospitalization for treatment of ADRs (Kusserow 1989). "The estimated annual costs of drug-related hospital admissions of the elderly, along with their subsequent treatment, was $4.5 billion in 1983" (Lipton and Lee 1988). Also linked to ADRs is the consumer's use of more than one pharmacy (Fincham 1988) and inadequate communication between doctors and older patients (Klein 1985).

Older consumers were found to have low levels of reliable health care knowledge, coupled with a generational unwillingness to ask questions of health professionals. In testimony before the Inspector General of U.S. Department of Health and Human Services, it was reported that only 2% of older adults asked ANY questions of their doctors -- about diagnosis, recommended tests, or prescribed medication and other forms of treatment (Kusserow 1989).

A comparison study of patients discharged from a Boston hospital -- with and without lengthy explanations by their doctors of the regimen prescribed -- found no difference in medication knowledge one month later (Klein 1985), a communications challenge for both professionals and consumers. For U.S. adults over age 16, one study indicated that 20% could not follow written instructions that stated, "Take two pills twice a day" (Mallet and Spruill 1988). Older adults may

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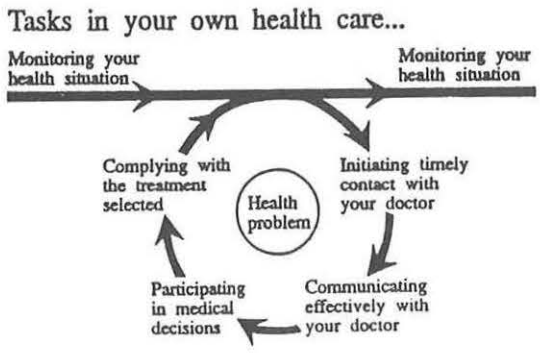
have both reading and comprehension problems, compounded typically by loss of visual acuity.

The problems involved in the relationship between health care consumers and health care professionals are complex (Vickery 1990). Clearly, these problems can not be significantly improved without simultaneous address by consumer and health educators AND the persons involved in continuing education programs for health care professionals. After further field testing of the program materials with older health care consumers, recommendations to appropriate professional associations will be made in mid-1993.

Program Design

A flow chart was created by the Instructional Materials Designer to help family caregivers visualize five specific "tasks" for the health care consumer to carry out as partner in his/her own health care.



The five-task concept is then applied to the caregiver's role as manager of the health care of dependent older family members.

Program components include: 1) an hour-long video for use during the ongoing family caregiver training program; 2) a complementary folder of original print materials for distribution to family caregivers (diagrams, checklists, worksheets and fact sheets); and 3) a packet of print materials for program coordinators (training leader's guide, videoscript, bibliography and evaluation instruments).

The program materials were introduced and tested in a single county in May 1992. Revised materials were sent in September 1992 to Extension Agents in the 37 counties already trained to conduct local caregiver training programs, with guidelines for expanding the training and reporting on program impact. An Extension Home Economics Agent and two representatives of her local aging network from 30 additional counties took part in team training in January-February 1993, and received direct training in the use of the new materials. Evaluation instruments include pre- and post- training surveys and a two-months later follow-up measurement.

Data collection as of June 1993 will be reported to the funding source in July 1993, and will be made available to anyone requesting a copy of that report.

Short-term benefits of the program are being measured in terms of improved knowledge and decision-making skill, and in reduced stress among family caregivers as health care consumers. Additional benefits are expected to include the improved health care of both caregivers and care receivers. A long-term, anticipated benefit of the program is the more appropriate, efficient use of the health care system by more knowledgeable, responsible consumers -- and a reduction of inappropriate demand on the health care system.

Review of program materials by representatives of other organizations in the health and aging networks resulted in a unanimous recommendation to adapt the materials for use with a variety of audiences in more flexible settings. A proposal to fund such a project, plus a new segment on health care costs, has been submitted to an appropriate foundation.

Implications for Consumer Educators

Some of the generalized lessons of consumer education require qualification when applied to the problems of older health care consumers. For example, grave limitations in the availability, accessibility and affordability of local health care may make the idea of investigating one's options or asserting one's rights a moot question. And advising consumers to shop for the best price for medications may lead to medication problems if there is no single doctor or pharmacist who reviews all the medications being taken.

If educational materials for older health care consumers are to be effective, they must incorporate the research findings from multiple disciplines which have addressed individual problem areas: communication between consumers and health care professionals; older adult usage of prescription medicines, non-prescription products and nutritional supplements; the factors involved in polypharmacy; the causes and costs of adverse drug reactions; the multiple reasons for non-compliance; and proven instructional techniques for older audiences.

Audiences of older adults will benefit from

special attention in the design and delivery of instructional materials. Research suggests the employment of such techniques as: providing as much structure as possible...using slow pacing of material... discussing one subject or task at a time...matching A-V message to verbal, point by point...avoiding bright colors, excessive contrast and glossy surfaces (Jinks and Baker 1987).

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