

ALLIANCE FOR AGING RESEARCH



*One
Final Gift*

HUMANIZING THE END OF LIFE
FOR WOMEN IN AMERICA

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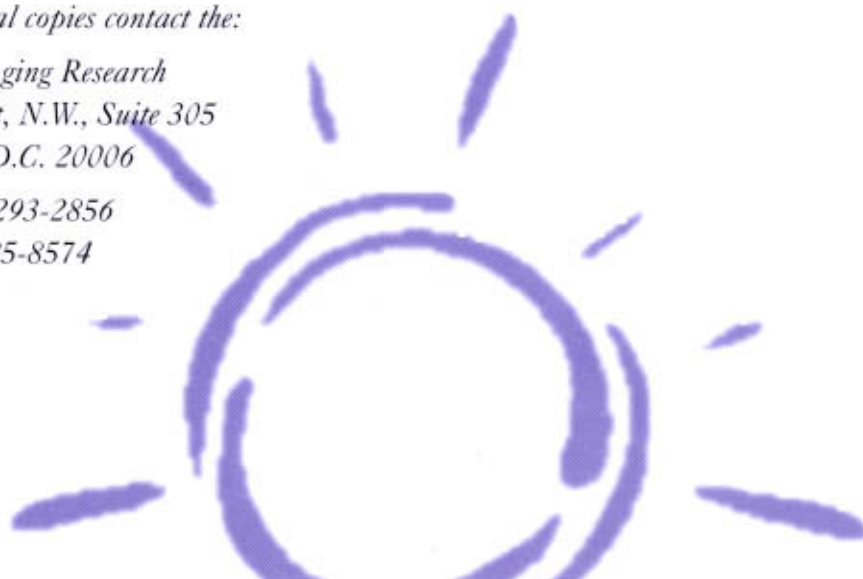
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EXECUTIVE SUMMARY

Death comes to all men and all women. The end of life is one of the great universal experiences, along with birth and life itself. So why develop a report specific to women and their care at the end of life? Women, like men after all, die just once. But because of greater survival into very old age by more women, the face of the worldwide longevity revolution is predominantly a female face. The U.S. and most of the world are witnessing rapid growth in the numbers and proportion of the very old in their populations. Within the oldest age groups (over age 95), American women outnumber men by a ratio of nearly four to one. Wise social planning requires better understanding of the medical and social support needs of the longest lived, ultimately making way for a humane and life-affirming death at the end of a long life; an end that we would all wish for ourselves and for our loved ones.

Women and men in our culture tend toward different experiences when death comes. The reality of life's end varies widely in terms of age, location, and attending conditions, all of which are determined in large measure by gender. Many older women in the United States face the end of their lives in ways that are fundamentally different from men. They do so in a medical culture that intrinsically is not designed to meet their special and often overwhelming needs. Within the context of this lack of knowledge and infrastructure, families and community-based social service agencies struggle to provide safe and comfortable living arrangements; social, emotional and spiritual support; and help with finances, transportation, meals and daily personal care.

A significant number of gaps in the knowledge base define the research agenda concerning women at the end of life. The under-representation of women as research subjects, which persisted over many years, leaves us today with limited information and understanding of many disease processes in older women and of how women fare in the medical care system. Still less information and knowledge exist about the passage of older women through the last years of their life until death. Among the questions: What should be the goals of care for an older woman near the end of her life? When should there be a transition from life-prolonging care to comfort care? Who addresses her non-medical needs? How should a woman and her family be brought into discussions and decision making on these critical issues? How can quality care be delivered and evaluated using the combined resources of family, community, and medical and social service systems?

These questions arise in the context of a medical care system poorly aligned with the needs associated with

the chronic health problems of older people. It is a system that still trains its professionals, provides care and pays for services based on the needs of patients with acute medical conditions and serious injuries. It is a system primarily oriented to the young and middle-aged with health insurance designed to cover acute medical problems, and largely unfamiliar with community-based aging and social services. Community-based service agencies and volunteers typically work with limited resources. They may have only fleeting interactions with the medical care system or with other social service agencies. These questions also confront millions of families that are coping with the consequences of a longer life span for women that did not exist just a generation ago.

Until quite recently, women's health was considered to be synonymous with reproductive health. Historically, very little research attention has been directed to the complex health issues that affect women in all stages of their lives. This is now beginning to change.

Improving care at the end of life for older women will require changes in the way medicine is practiced, how care is reimbursed, how community-based health and social services operate together, how professionals in many disciplines are trained, how information about long-term care and end-of-life issues is transmitted to the public, and, underlying all this, how Americans view the end of life itself.

The Alliance for Aging Research has prepared this report to organize the complicated and intertwined issues of women and their care at the end of life. It is intended to stimulate discussion and action by grant-makers, policymakers, and women and men of good will who can effect changes for the better in how our fellow human beings receive care and support in the final phase of life. A panel of seven prominent authorities from some of the nation's top centers of learning reviewed the material. They included experts in gerontology and geriatrics, hospice and palliative care, caregiving issues, bioethics and health policy. The advisory panel drew upon scores of recent studies, surveys, research findings and published reports.

At the core of this report are *Seven Essential Truths* about the reality of women and the care they receive and give at the end of human life. Within each of these areas, the advisory panel has identified missing information to guide the research agenda. These missing pieces are listed in sections titled *Where are the Gaps?* The panel has also developed recommendations for policymakers, listed under headings *What Should be Done?* These recommendations have the full endorsement of the Alliance for Aging Research.

Seven Essential Truths ~ Women and Care at the End of Life

- Truth No. 1* Women live longer than men, but they are more likely to suffer from the effects of chronic disease, including declining functional and cognitive status.
- Truth No. 2* The majority of older women in the U.S. die outside of the home, in nursing homes or hospitals.
- Truth No. 3* Fragmentation and limited financing for long-term care services, especially toward the end of life, result in unmet care needs for older women.
- Truth No. 4* Despite increasing reliance on care at home, there is little support for family caregivers.
- Truth No. 5* Most married older women outlive their spouses; consequently many often suffer a steep decline in economic status.
- Truth No. 6* Older women are more likely to live alone, with an ensuing complexity of health care and other needs near the end of life.
- Truth No. 7* Society can provide and afford much better care at the end of life that respects women's preferences, provides emotional and physical comfort, fosters family peace and meets spiritual needs.

Key Recommendations

- The Department of Health and Human Services must support increased research and training into better care and treatment options for chronically ill older women at the end of life.
- Health care and social service providers need to better understand and adopt the principles of palliative care in settings where older women live and die.
- New collaborative channels must be established among various agencies which provide community and social services, and medical care institutions. This will improve the quality, continuity and appropriateness of end-of-life care for older women.
- As complex and burdensome caregiving responsibilities are increasingly shifted from medical settings to the home, family caregivers must be given better preparation, information, and support in order to fulfill this role.
- Policymakers should reexamine long-term care (Medicaid) policies that currently force married people to spend down to poverty levels. Governmental policies should also reform the means of financing home and community-based long term care to support a continuum of care to the end of life.
- A national dialogue on humane care at the end of life, one that reflects the preferences, values and beliefs of families and communities, must be encouraged and facilitated by leaders from the private sector, businesses, foundations, the media, religion and medicine.

One Final Gift

One risk of a report such as this is that the deep human feelings surrounding the emotionally-laden issues of care for the dying can be blunted in the process of assimilating data, and the reader of the report can thus become desensitized. Therefore, the reader is urged to keep in mind the human face of the subject at the heart of this study. It is a female face; it could be your mother, your grandmother, your wife, your sister, your aunt, your neighbor or your best friend. In time, she could be you.

The older woman of today lived through the deprivations of the Great Depression. She witnessed the rise of high speed travel and communication, the spectacular growth of medical technology, and the emergence of a mass community. She saw her children grow up in a world completely different from the one she knew as a child and experienced the difficulty of adjusting to a dispersed family. And through it all, she gave us the gift of her knowledge, wisdom and love. Now she is an older woman at the end of her life. Can we help her claim her own innate power over life's end and, in doing so, give her one final gift — humane and compassionate care at the end of life? And by taking leave of her life, may she be the teacher once again, showing us how to achieve a good death — giving us one more final gift.

TRUTH No. 1

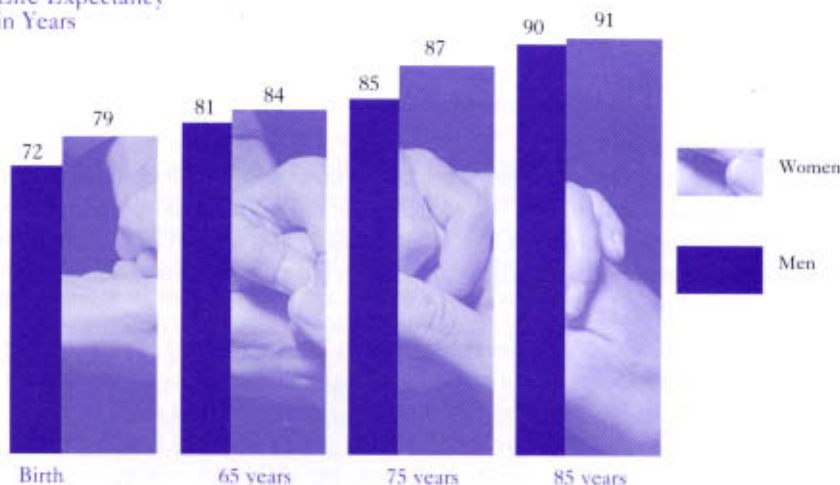
Women live longer than men, but they are more likely to suffer from the effects of chronic disease, including declining functional and cognitive status.

Americans are getting older in larger numbers than ever before and the increased life expectancy of women has resulted in a dramatic growth in the older female population. From birth on through the oldest ages, women's life expectancy outpaces that of men (see *Figure 1*). Women in the U.S. outlive men by an average of six years and therefore tend to die at later ages than men. In 1995, 73 percent of all deaths occurred among people age 65 and older and 24 percent occurred among people age 85 and older. Particularly striking is the relatively high percentage of deaths — 16.4 percent — that occur among women over age 85. (National Center for Health Statistics, 1997)

As a result of their longer life expectancy, older women greatly outnumber men of the same age. The ratio of men to women in the population is illustrated in *Figure 2*. While at birth, males outnumber females, this changes drastically in later ages, to the point

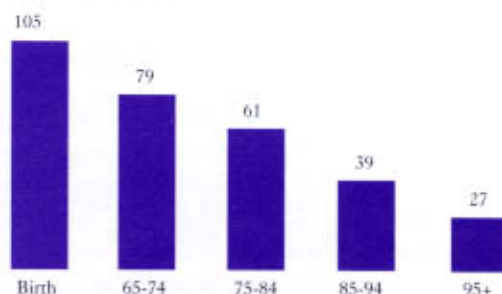
Figure 1
Life Expectancy at Birth and Older Ages
for Men and Women: U.S., 1995

Life Expectancy
in Years



Source: National Center for Health Statistics, 1997

Figure 2
Number of Men per 100 Women
by Age: U.S., 1994



Source: U.S. Bureau of the Census, 1996

where women outnumber men by a ratio of almost four to one after the age of 95. In 1994, women made up nearly two-thirds of all people over age 85, almost 2.5 million people, compared to 982,000 men. (U.S. Bureau of the Census, 1996).

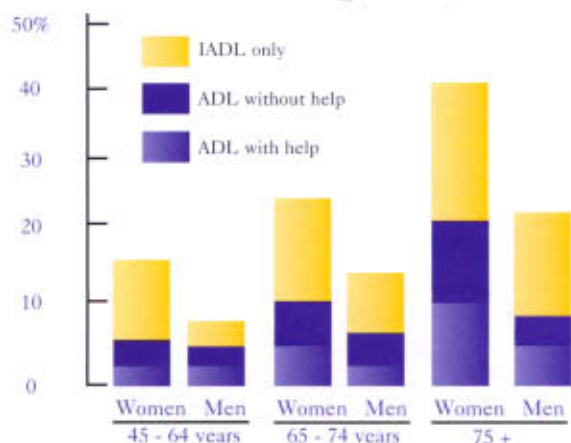
The shift this century from quick deaths due to acute, infectious diseases and accidents to prolonged ones from long-term, chronic disorders has had a profound effect on women. Women, especially as they age, are more likely than men to suffer from chronic conditions such as arthritis, osteoporosis and related fractures, Alzheimer's disease and incontinence.

Disability is one major consequence of living with a long-term chronic condition. In every age group more women than men are functionally or cognitively disabled. In 1991, 24 percent of women aged 65-74 years and 41 percent of women 75 years of age or older who lived in the community reported suffering from some type of disability. Disability is measured by having difficulties with instrumental activities of daily living (IADLs), such as managing money, doing housework, preparing meals, shopping for groceries and clothes, and getting to places out of walking distance; and activities of daily living (ADLs), which include dressing, bathing,

grooming, toileting and eating. At each age, the proportions were higher among women than among men as shown in *Figure 3*.

Women are also more likely to live with comorbidities — that is, more than one chronic health condition at a time (see *Figure 4*). People with more than one condition have more physician contacts and are more likely to be hospitalized each year than people with one condition. As chronic conditions increase in number so do the chances of having difficulties with personal care and basic daily living tasks. (Institute for Health and Aging, 1996)

Figure 3
Disability Status of Noninstitutionalized Men and Women at Selected Ages: U.S., 1991



Source: National Center for Health Statistics, 1996

With their long lives and cumulative disability from chronic disease many women need support and assistance toward the end of their lives. Physical or cognitive limitations can result in a wide range of needs, from help with housekeeping, to assistance with daily personal care, to round-the-clock support. Many chronic conditions, such as incontinence, Alzheimer's disease and hip fracture from osteoporosis significantly increase the odds of being placed in a nursing home or hospital during the last days of life.

The very nature of chronic diseases means that one can live with the condition for a long time. It is difficult to accurately predict life expectancy for such chronic illnesses as Alzheimer's or Parkinson's disease, which have a long, slow decline, as well as for such prevalent conditions as congestive heart failure, from which patients may suffer for years, yet tend to die unexpectedly. It may not be possible to do any better than we can today in terms of predicting how long one will live with these kinds of conditions. As a result, the boundary is increasingly blurred between living with a chronic illness and dying from it, making it difficult to know when to shift from life-prolonging treatment to palliative care.

Where are the Gaps?

How can epidemiological and other survey data tell us more about gender differences for such areas as chronic disease occurrence, disability, treatment and preferences for care?

How do chronic illnesses determine where and how older women live and die?

What effect do certain life-prolonging interventions have on quality of life?

When interventions can no longer improve both length and quality of life, when should the focus shift from prolonging life to palliating symptoms?

Given difficulties in prognostication for chronic illnesses, how should decisions be made about balancing interventions designed to lengthen life versus those designed to give comfort?

What Should be Done?

Compile, review and analyze existing data sets for gender differences.

Conduct additional research on the impact of chronic disease and disability on older women at the very end of life.

Better train physicians and other health care providers to care for chronic illnesses and to more openly discuss preferences for life-prolonging versus palliative care at the end of life with their patients.

Support research to develop inexpensive and non-invasive prognostication screening tools for use by physicians in their offices.

Figure 4
Percent of Women and Men with Comorbidities



Source: Institute for Health and Aging, 1996

TRUTH No. 2

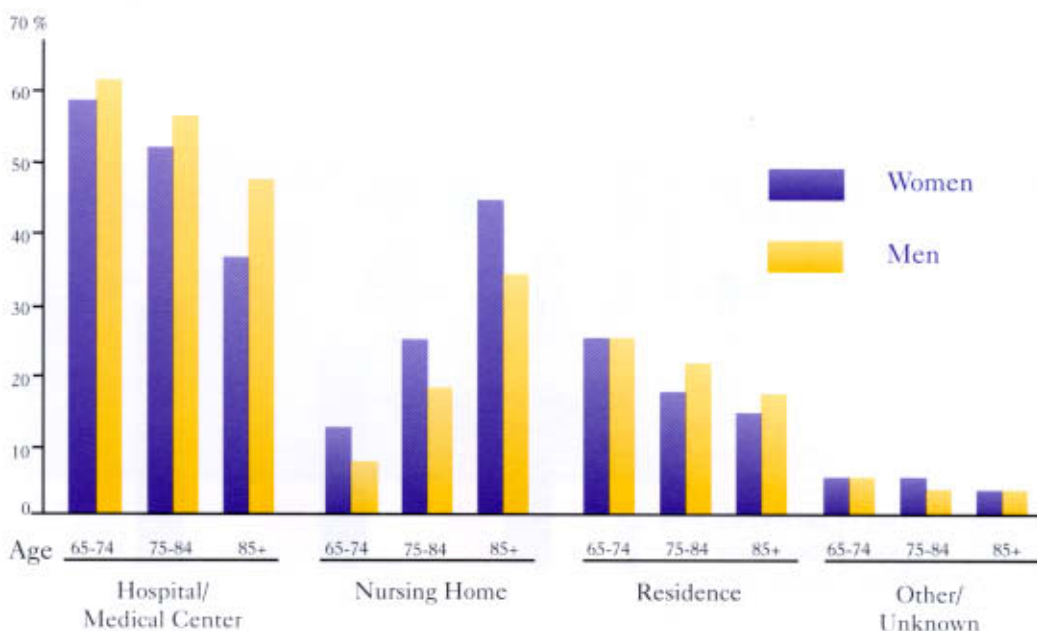
The majority of older women in the U.S. die outside of the home, in nursing homes or hospitals.

Throughout this century, the location of death has moved gradually from the home to the hospital or nursing home. In 1939, 39 percent of the total population died in institutions; by 1992, this number had increased to 81 percent (National Center for Health Statistics, 1996B). Based on information from the National Mortality Followback Survey, there appears to be a trend away from deaths in institutions for the overall population, as this number decreased to 73 percent in 1994. In the over-65 age group, 75 percent of men and 78 percent died in nursing homes or hospitals. Among people over age 85, 80 percent of men and 84 percent of women died in nursing homes or hospitals, while 13 percent of women and 17 percent of men died at home. (National Center for Health Statistics, 1996C) *Figure 5* shows the locations of death for men and women in different age groups.

Many factors may compete with patient preference in determining the location of death. A recent Dartmouth study found significant regional variations. People in the South and Northeast were almost twice as likely to die in the hospital as those in the Western United States. There were fivefold differences across regions in the percentage of patients who spent time in intensive care in their last six months, even in communities with similar populations. Study authors believe that this variation in rate does not likely reflect informed patient preferences, but reflects the availability of facilities and physician treatment patterns. (Dartmouth Atlas of Health Care, 1998)

Another compelling study provided several insights into the lives of men and women at the end of life, including the numbers of days they spent in different settings. *The Survey of the Last Days of Life* examined the last 90 days of life of people age 65 and older who died in Fairfield, Connecticut in 1984 and 1985. On average, men age 65 and older and women age 65-84 spent more than half of their final 90 days in the community. The exception was among women age 85 and older who spent more than half their final days in an institutional setting, either a nursing home or hospital (see *Figure 6*) (Brock, Holmes, Foley and Holmes, 1992).

Figure 5
Percent of Men's Deaths and Women's Deaths that Occur in Different Settings: U.S., 1994



Source: National Center for Health Statistics, 1996C

The principles of palliative care—aggressive treatment of pain and other symptoms, and conscious attention to improving or enhancing quality of care—have not yet been well-integrated into many end-of-life settings. Palliative care is particularly important for older women, as this group has been found to be at heightened risk for the undertreatment of pain (Ahronheim, 1997). Between 25-50 percent of older adults living in the community and 45-80 percent of nursing home residents experience chronic pain (Roberto, 1997). Yet studies have shown that 40 percent of patient with needs for pain management received ineffective pain care, including infrequent dosages, ineffective medication or no medication at all (Wagner, 1996). Other distressing symptoms, including shortness of breath, depression, loss of appetite and nausea affect many patients at the very end of life. While in many cases, effective strategies exist to relieve these symptoms, they are poorly implemented, due primarily to inadequate physician knowledge (Institute of Medicine, 1997).

Another important concern related to where older women spend their final days is the practice of transferring nursing home residents into the hospital just prior to death. Among nursing home residents age 65 and older, 28 percent had at least one hospital stay during the year, and of all the hospital stays, 12 percent ended with death in the hospital (Murtaugh and Freiman, 1995). These transfers are not only disruptive for patients and their families, but carry with

them a high risk of complications as well. As such, this practice may not represent optimal care for dying nursing home patients.

Where are the Gaps?

What is the quality of terminal care delivered in the various settings of the end of life for older women?

How much does patient preference versus other considerations (family needs, costs, medical care services) determine the site of death?

Why do transfers from nursing homes to hospitals at the very end of life take place, and how can nursing homes take care of the full range of needs of the dying patient?

How can the hospice care model, including the principles of palliative care, be better utilized and brought into settings where older women tend to die, including hospitals and nursing homes?

What Should be Done?

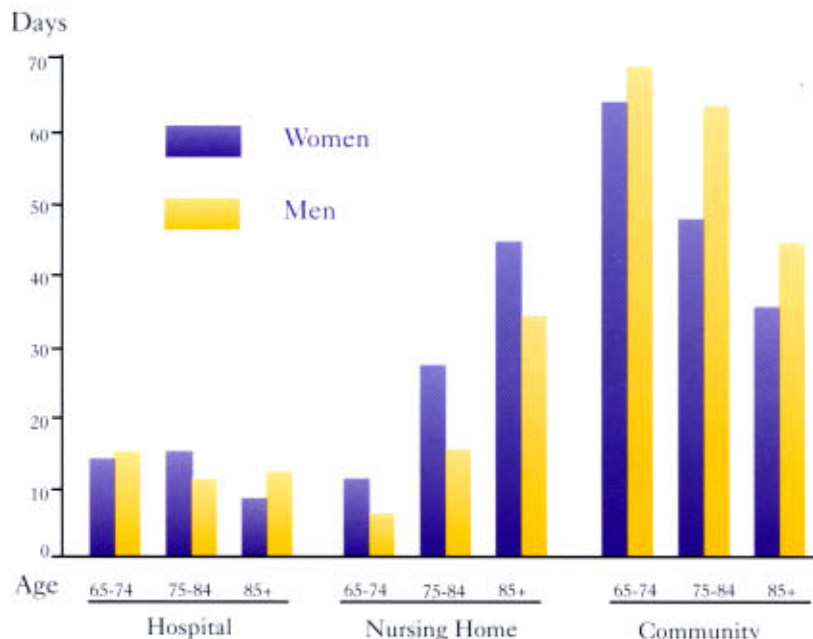
Utilize the existing National Followback Mortality survey to ask important unanswered questions about end-of-life experiences for older women and men and to determine unmet needs of dying people.

Conduct studies on the quality of care delivered at different sites of death and the determinants of receiving care at different sites of death, especially the relationship between preferences and other factors.

Fund palliative care models for a variety of medical conditions affecting older women in a range of end-of-life settings and disseminate the findings.

Examine and reevaluate the role that nursing homes should play in end of life care, and support the development of better care in all locations where older women die.

Figure 6
Number of Days per Person Spent in Different Settings in the Last Days of Life: Fairfield, CT, 1984-85



Source: Brock, Holmes, Foley and Holmes, 1992

TRUTH No. 3

Fragmentation and limited financing for long-term care services, especially toward the end of life, result in unmet care needs for older women.

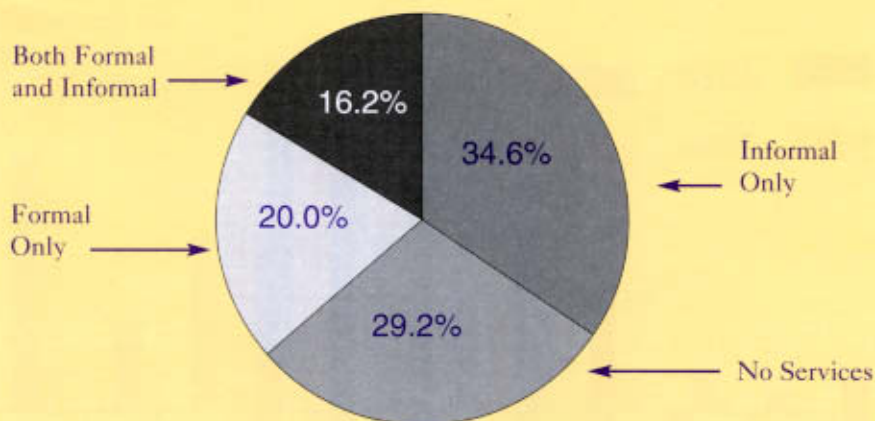
The unmet health and long-term care needs for older people are great. The 1987 National Medical Expenditure Survey indicated 29.2 percent of people over age 65 with functional difficulties received no formal or informal assistance of any kind. Even among severely disabled persons with difficulties performing three or more activities of daily living, more than one-half did not receive any formal services (Short and Leon, 1990). A study in Springfield, Massachusetts found that 56 percent of people with difficulties performing many activities of daily living had unmet needs for care. This resulted in such consequences as not getting to the bathroom, falling while moving from a bed or a chair, or not bathing or showering. (Institute for Health and Aging, 1996)

When assistance is needed by older people, most often families play a major role in providing care. As shown in *Figure 7*, the 1987 National Medical Expenditure Survey indicated that 34.6 percent of older persons with functional difficulties relied solely on family and friends for help.

There are several reasons why there is relatively low use of formal, paid services and reliance on families for care. First, Medicare covers part-time home health services for a limited time period only when very specific guidelines are met. This does not cover the majority of needs for older, frail people who wish to remain living at home independently. Also, low pay and limited benefits for home health aides make this profession an unattractive one for many workers.

“...community-based aging, social service and volunteer agencies operate with little coordination with the medical care system.”

Figure 7
Percent of Disabled Older Persons Receiving Formal and Informal Home and Community Services: U.S., 1987



Source: National Medical Expenditure Survey, 1987

When remaining in the home is no longer a viable option, Medicaid funding for nursing home coverage is limited to the poor. Families may be forced to “spend down” to obtain Medicaid assistance, a process that reduces the spouse to only about \$4000 in assets along with the house and one car. Until forced into poverty, family assets must be used to pay out-of-pocket for nursing home care, which averaged \$37,000 per year in 1995 (Lewis, 1997). Less than two percent of Americans have any type of long-term care insurance (Giorgianni, 1997).

Finally, care services are fragmented. That is, many communities have multiple but uncoordinated service providers, some non-profit and some for-profit, that offer a multitude of services, from transportation and friendly visiting to skilled nursing care. In these communities, problems with fragmentation are made worse by varying eligibility requirements for specific services. Others lack any alternative services to care in the home, such as adult day care. The result is that communities are not able to provide comprehensive home and community care services. For families, lack of familiarity with available assistance and limited access make it difficult to navigate existing systems and coordinate formal help with family care. To further complicate matters, the community-based aging, social service and volunteer agencies operate with little coordination with the medical care system.

Where are the Gaps?

How can needs for long-term care, especially for chronic illnesses that result in death, be better met by the existing health care financing sources, including Medicaid, Medicare and private insurers?

What kinds of qualified health professionals are needed to provide the best and most efficient care for all older people at the end of life and how should they be trained?

How should an individual older woman's care needs and her existing strengths and weaknesses be assessed? Who can conduct these assessments? How frequently should assessments be conducted?

How can existing community-based aging and social services be brought together to reduce duplication and to address unmet needs?

How can the medical care and social service systems collaborate to support the functioning of older women?

What Should be Done?

Conduct research to better define and assess end-of-life care needs.

Create community focal points for information about aging, long term and chronic care services and assure that any information and referral services are widely and consistently marketed so the public is aware of them.

Provide guidance to older women or to family members to help them assess needs and to understand services and eligibility.

Foster collaboration among the multitude of community agencies that play a role in providing services to older women by bringing them together to support a common goal, such as public education or information and referral.

Better train and compensate home health aides and household help for the important work they do.



TRUTH No. 4

Despite increasing reliance on care at home, there is little support for family caregivers.

As part of the drive to control health care spending, a greater proportion of the care of the seriously ill is being shifted to the home. Today, complex medical procedures such as infusion therapy, kidney dialysis, surgical wound care, total parenteral nutrition and respirator care are delivered at home by family members. Even when the necessary care needs are eligible for Medicare home care services, skilled nurses or home care aides can assist a only few hours a day or less, and the bulk of the care is placed on family members or is paid for out-of-pocket. In other families, required care may not be medical in nature, but can be demanding in other ways. The increased prevalence of Alzheimer's disease is just one example of the burden that is being placed on caregivers at home.

Most caregivers are women. The 1997 *Study of Family Caregiving in the U.S.* found that three-quarters of caregivers are women, that most of the care recipients are women, and that the average age of the care recipients is 77 years (National Alliance for Caregiving, 1997). Earlier surveys indicate that adult daughters made up the largest percentage of family caregivers — 29 percent — with wives comprising 23 percent, and husbands 13 percent. The average age of caregivers was 57 years, with 25 percent between the ages of 65-74 and 10 percent 75 years old or older. (Stone, Cafferata and Sangl, 1987)

The 1997 *Study of Family Caregiving* indicated family caregivers provided an average of 18 hours of care a week, with the most intense situations demanding an average of 56.5 hours of care a week. There are currently no published estimates of the economic value of time devoted to caregiving.

While many caregivers report that there are positive aspects to caregiving from emotional satisfaction, new found inner strength, or feelings of competence, the demands involved can also take a heavy toll. Conflicts between work and caregiving, physical injuries, emotional problems, isolation and exhaustion are just some of the difficult effects that have been reported. (Brown and Mulley, 1997; Schultz, Visintainer and Williamson, 1990)

Family caregivers need training, support and respite when demands of caregiving are great. When medical procedures are delivered in the home, caregivers need to be able to work in partnership with health care professionals; receive continuity of care between hospital and home; and be provided with follow-up from the physician or hospital to assure appropriate medical care. Family caregivers also need emotional support and recognition of the important, often demanding role they are playing.

While there are some innovative programs to support caregivers, these tend to be fragmented and scattered. Some large employers have recognized the demands of caregiving and have responded by offering flexible work hours and information. California established a network of 11 family caregiving resource centers for brain-impaired adults that help families assess needs, locate services, and develop a comprehensive care plan for their loved one. Disease specific support groups with local affiliates can provide a tremendous amount of emotional, physical, and sometimes even financial support for caregivers.

Where are the Gaps?

How can local and national programs be enhanced and expanded to better logistically, emotionally, physically and financially support caregivers?

How can information about caregiving be made more widely available?

How can more flexible working conditions be arranged for caregivers?

How can families engage in frank discussions on personal preferences and options for care at the end of life early in the process before a crisis occurs?

What Should be Done?

Develop new and expand existing national or local programs for caregiver support and information.

Support caregiver resource centers and increase availability and affordability of respite care and volunteer caregiving programs.

Develop simple informational materials that discharge planners can use to refer families to local aging service organizations.

Encourage physicians to work more effectively with caregivers or offer "home nursing" training for caregivers.

TRUTH No. 5

Most married older women outlive their spouses; consequently many often suffer a steep decline in economic status.

Nine out of ten married women will experience widowhood at some time during their lives (Alliance for Aging Research, 1992). The loss of a husband, with the accompanying reduction in Social Security and pension benefits, means that many women must make fewer economic resources stretch to cover their longer life span. Some women become impoverished at a late age as a direct result of spending family resources to care for a husband or other family member during an illness.

Nearly three-fourths of the four million elderly poor in the U.S. are women. Economic status for older women today is influenced by long lives and often limited or non-existent work history. The lack of financing for long-term care in the U.S. also places a significant burden on many older women. Women who lived lives of relative comfort often first experience poverty or the threat of poverty as they enter old age alone after expending family resources on care for their husbands or with the loss of husband's pen-

sion benefits after his death. (Lewis, 1997) The exact number of women who face this is unclear.

Social Security is the primary source of income for 63 percent of older men and women. For 14 percent, most of them women, it was the only source of income in 1992. The average monthly Social Security pension benefit was \$601 for women. In 1992, about 22 percent of older women were eligible for private pensions. Women's pensions averaged \$5,432 per year — about half the average amount for men. (Lewis, 1997)

While the combined results of widowhood, low wages and limited work history or years of poverty cannot be changed, forced poverty brought on by long-term care spending is a frightening problem facing older women and their families. It is also an issue that is poorly understood by the public and even by many professionals, and poorly addressed by public policies.

What does “spend down” really mean? A True Story

Joan is a gifted elementary school teacher aged “60ish.” Until last year, she and her husband Harold were “on top of the world.” Though he was close to 70, he worked part-time, lunched regularly with friends and played golf several times a week. They lived in a well furnished, and comfortable condominium. Then he had a stroke. He recovered, went through a rehabilitation program, and was nearly back to his old self again. But several months later he had a second stroke and then a third. With each stroke, he lost more ability to function. With his fourth stroke, the doctor said rehabilitation therapy would no longer help — Harold now needed round-the-clock care, which could best be provided in a nursing home.



cont. page 12

TRUTH No. 5

(cont.)

Joan took him home one more time with a wheelchair, hospital bed, and other paraphernalia. She was upset when she found out Medicare did not cover any of these expenses since Harold no longer met the criteria for home care, and she provided complete care for him during the rest of the summer. Then the school year started again, and with it, Joan's job. While Joan went back to work, their son and neighbors helped with Harold at home, but Harold was still often left alone. Joan often got calls at work to solve such problems as falls and bowel accidents. After more than 20 absences from work she realized the situation was no longer manageable and began looking for a home health aide. She realized then that she couldn't afford daily help at home, and so she was forced to begin investigating nursing homes for Harold.

After much anguish she found a good facility close to home and Harold moved in. She believed since they had both worked all their lives and paid "all their taxes and Social Security" that financial help would be there when they needed it. Joan spent every evening with Harold and applied for Medicaid. To her horror, she found she would have to "spend down" virtually all of their savings and investments before any assistance would be available. The day after the Medicaid application was turned down the nursing home presented her with its first bill—for \$18,000 for four months.

Now each month, Joan's expenses for Harold's care by itself exceed her income by more than \$1000; and that's before their home mortgage and basic bills are paid. According to current Medicaid rules, no payments will be made for Harold's nursing home care until Joan is left only with her condominium (with its mortgage), her car, her wedding ring and about \$4000 in cash. Until then, it is an open question whether the family savings give out before Harold's death comes. Whichever happens first, Joan will face her own future with a severely diminished financial picture and bleak hopes for her own security.



Where are the Gaps?

How many families are forced into poverty as a result of current financing policies?

How can current financing policies which favor the lifespan and illness patterns of men do a better job of paying for the care that women are likely to need for themselves or after outliving their husbands?

How can women and their families improve their preparation for the financial issues that can come with old age?

What Should be Done?

Review and amend national long-term care policies that force poverty on older people and their surviving spouses needing care at the end of life.

Seek ways to create links between medical and social services and financing structures that will better serve older women's health care needs at the end of life.

TRUTH No. 6

A large number of older women live alone, with an ensuing complexity of health care and other needs near the end of life.

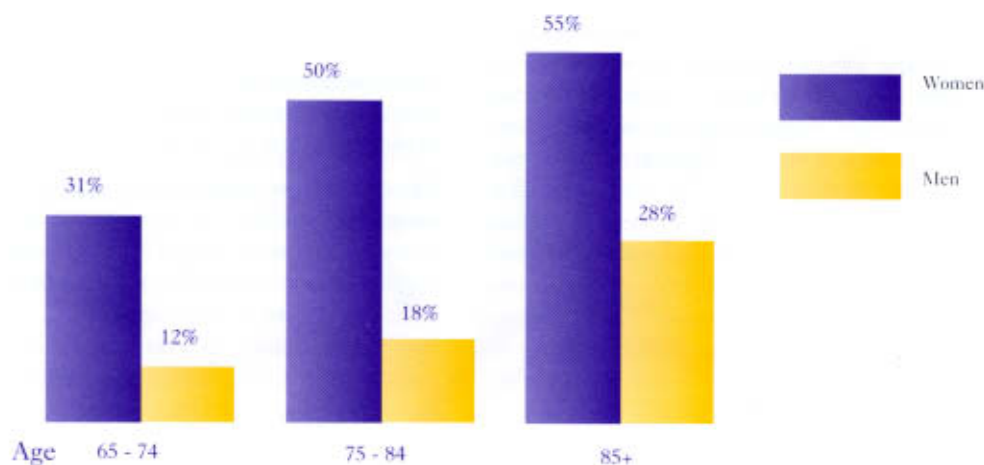
Older women are far more likely than older men to live alone, according to a 1993 report by The Commonwealth Fund. This is a reflection both of women's longer life expectancy and their tendency to marry men who are older. Men are also more likely than women to remarry in the event of the death of a spouse or divorce. In 1993, 9.4 million people aged 65 and older lived alone. Of this number, 7.4 million were women and 2 million were men. In other words, almost 80 percent of all people over 65 living alone were women. (U.S. Bureau of the Census, 1996)

As they age, women are more likely to live alone. As shown in *Figure 8*, in 1993, 31 percent of noninstitutionalized women between the ages of 65 and 74 lived alone, compared with 12 percent of men. This continued to rise, until by age 85, 55 percent of women lived alone.

Older women live alone for many reasons, including widowhood, divorce, distance from children and other family members, and never having married. In 1995, nearly half of women over age 65 (47 percent) were widowed compared to 14 percent of men in the same age group. Of women in this age group, 6 percent were divorced and 4 percent were single. The generation of women in their 80's today who were of childbearing age during the Great Depression also had among the lowest birth rates in history. This means that about 25 percent of these women have no living children to help with their care.

Living alone does not necessarily mean that an older woman is abandoned by her family in later life. Many older women choose to live alone after a spouse dies, but may not have close-by family or friends to rely on for assistance. Without regular support or access to formal home care, an older woman living alone is at risk of losing her independent lifestyle (The Commonwealth Fund, 1993). Even with a family support system, the logistics of providing needed care for an older woman living alone with a chronic illness or disability can be very difficult, due to lack of financial resources, physical distance from family and constraints on other family members, such as work and children of their own.

Figure 8
Percent of Older Men and Women Living Alone: U.S., 1993



Source: U.S. Bureau of the Census, 1996

TRUTH No. 6

(cont.)

Other implications of older women living alone can be that symptoms of illness or depression often go unrecognized or steps to increase safety in the home are not taken. When a primary caregiver is not readily available for an older woman who needs help with activities of daily living, admission to a nursing home may be the only alternative. According to the American Association of Retired Persons, women make up three-quarters of all nursing home residents 65 years or older.

“Without regular support or access to formal home care, an older woman living alone is at risk of losing her independent lifestyle.”

Although widowhood is the primary reason for living alone, society no longer adheres to long, formal periods of mourning. Widow-to-widow outreach programs are operated in some communities, but these serve only a fraction of widows. Little is known about the desire on the part of widows to participate in these or other outreach programs or what widows would consider most helpful. Bereavement counselors are more often being called upon in the wake of a sudden, violent death, such as the death of a child, but bereavement counseling is not widely used by older persons and their families outside some hospice programs.

Where are the Gaps?

What characterizes the situations and preferences of women living alone, and what are the approaches needed to identify and serve the care needs of this group?

How does living alone affect the overall health and well-being of older women?

Is living alone a risk factor for multiple health consequences? If so, can patients be screened and supports put in place that might help sustain physical and mental function?

Are there better living options for women alone? Can older women who are alone establish group living situations and provide care for one another or pool resources to hire paid caregivers? How can financial, housing, and legal barriers to these arrangements be overcome?

Are there programs and services that would benefit bereaved older women and their families? Who can develop and operate these services? How should they be assessed?

What Should be Done?

Develop primary care screening and assessment tools to identify and better serve older women living alone at risk of declining function.

Create and expand economical living options for older women.

Mobilize existing community resources to better identify, determine preferences and serve the needs of older women living alone.

Expand the availability and access to bereavement programs.

TRUTH No. 7

Society can provide and afford much better care at the end of life that respects women's preferences, provides emotional and physical comfort, fosters family peace and meets spiritual needs.

Two qualitative studies of consumers' views provide a picture of what Americans say they value about care at the end of life. Most Americans feel that death should not be the sole province of the medical care system, and many value a natural death, in familiar surroundings, in the presence of family and friends. The importance of spiritual and personal growth near the time of death for the dying person and for his or her family is important as well. The surveys also find that people want the time near death to be free from pain and unpleasant and frightening symptoms, and that patients and families should be provided with continuing information about what to expect and how to make informed decisions so that the patient's preferences are fully understood and honored. (Supportive Care of the Dying, 1997 and American Health Decisions, 1997)

These values, however, stand in stark contrast to how many deaths for older people take place today. In 1997, the *Annals of Internal Medicine* reported the findings from a survey of family members about the dying experience of more than 4,000 older (over age 80) and seriously ill people who died between 1989 and 1994. More than half the patients who died did so in hospitals and one-third of the elderly died in nursing homes. Nearly half of all patients were fed by tube or ventilated on a machine, and 40 percent of patients had severe pain most or all of the time in the last three days of life. (Lynn, 1997)

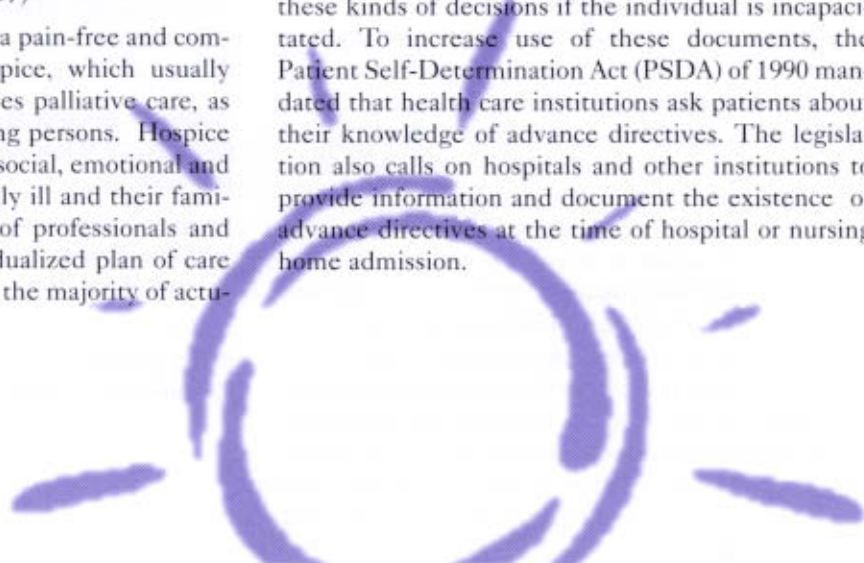
One answer for many people for a pain-free and comfortable death is hospice. Hospice, which usually takes place in the home, provides palliative care, as opposed to curative care, to dying persons. Hospice services also include supportive social, emotional and spiritual services to the terminally ill and their families. A multi-disciplinary team of professionals and volunteers coordinate an individualized plan of care for each patient and family, with the majority of actu-

al care being given by a family member or other person living in the home. In some locales, a hospice program also operates a facility to supplement or serve as an alternative to care at home.

In 1995, hospice programs cared for about 400,000 people — about 17 percent of people who died. Of the patients, 53 percent were male and 47 percent female. (Hospice Association of America, 1996). Hospice services became reimbursable under Medicare in 1983, and that program has done a great deal to increase the use, availability, and public awareness of hospice. However, while hospice care can enhance and support the dying and their families, access is limited for several reasons.

First, as most hospice care takes place in the home, a primary caregiver living in the home needs to present to care for the dying person. This requirement is simply not feasible for the large number of older women who live alone. Second, hospice eligibility under Medicare is limited to persons certified by physicians to have 6 months or less to live and who will forego aggressive medical care in exchange for palliative care that might not otherwise be covered. In addition to the emotional hurdle of admitting to oneself that remaining life is short, physicians are not able to accurately predict life expectancy for many complex chronic conditions, so this condition can be hard to meet.

One attempt at improving planning for care at the end of life has been the promulgation of advance directives — written, signed documents in which an individual specifies what medical treatment he or she would want or not want in the future, based on personal beliefs and preferences. A health care proxy also can be named — that is, someone who can make these kinds of decisions if the individual is incapacitated. To increase use of these documents, the Patient Self-Determination Act (PSDA) of 1990 mandated that health care institutions ask patients about their knowledge of advance directives. The legislation also calls on hospitals and other institutions to provide information and document the existence of advance directives at the time of hospital or nursing home admission.



TRUTH No. 7

(cont.)

The major impact of the PSDA has been to enhance the documentation of existing advance directives in health care institutions, but there is little evidence that it has resulted in greater completion of advance directives after admission (Bradley, 1998). In addition, nursing home staff tend to exclude many residents, the vast majority of whom are women, from discussions about advance directives because they believe them to be cognitively impaired (Bradley, Walker, Blechner and Wetle, 1997).

Even when patients do have advance directives, they often have little impact on or relevance to end-of-life decision making. Barriers to greater use of advance directives include their lack of specificity in treatment objectives, the difficulty of predicting when a given patient is near the end of life, and the fact that patients' preferences are simply not translated into practice, even when specified (Alliance for Aging Research, 1997). The concept of advance directives needs to be expanded to a greater vision of advance care planning which is both patient-focused and family-centered. Advance care planning focuses not only on communication and negotiation about the patient's values and goals for end-of-life care, but also on the development of contingency plans to honor these values and goals (Teno, 1996).

Much of the comfort in the dying process comes from spirit-filled experiences that defy everyday logic and the capacity for emotional healing and forgiveness within relationships (Byock, 1997). Dying persons and their loved ones are better able to concentrate on these essential aspects of the end of life when the dying person is free from pain and distressing physical symptoms, and in close proximity to loved ones. America's culture of death "defiance," embodied in the medical establishment, has far to go in providing spiritual comfort to those who are dying. A recent Gallup poll found that while more than half of Americans long for spiritual support at the end of life, only 36 percent would choose the clergy to provide it, and even fewer (30 percent) said that they would look to a physician or nurse for comfort (George Gallup International Institute, 1997.) Given the vast disparities in end-of-life experiences, greater efforts must be made to establish accountability for quality care in this arena at the individual, organizational and community levels. Work to measure and determine accountability for quality medical care of the dying within health care systems is now beginning. The purposes of quality assessment include improving

clinical services, assuring organizational accountability and conducting systematic outcomes research (Institute of Medicine, 1997).

Where are the Gaps?

How can care for the dying be brought more into line with patients' wishes and humane concerns?

Within the current financing structure, how well are hospices reaching persons eligible for their services? Should referrals to hospice be increased? If so, how can this best be accomplished?

How can the health care system move toward a more dynamic process of negotiation and communication about desired outcomes at the end of life? How can advanced care planning for the end of life be better integrated into medical care systems?

How can physicians best use opportunities to discuss end-of-life issues, including treatment and palliative care options, with older women and their families?

How can opportunities for spiritual growth and emotional healing be made a part of dying in America?

What Should Be Done?

Support programs that provide greater access to hospice for older women.

Promote opportunities for families to understand and discuss end-of-life issues to both increase awareness and provide a knowledge base they can draw on when faced with personal decisions.

Create ways that advance care planning tools can be used to better stimulate discussions between physicians and their patients and improve patient autonomy and decision making.

Continue to support assessment and measurement of the quality of end-of-life care and the experience of the dying person.

Support continued professional training and development needed to assure accountability and high quality end-of-life care.

Make information on the current quality of care for dying patients available for older people and their families in the selection of health care plans.

CONCLUSION

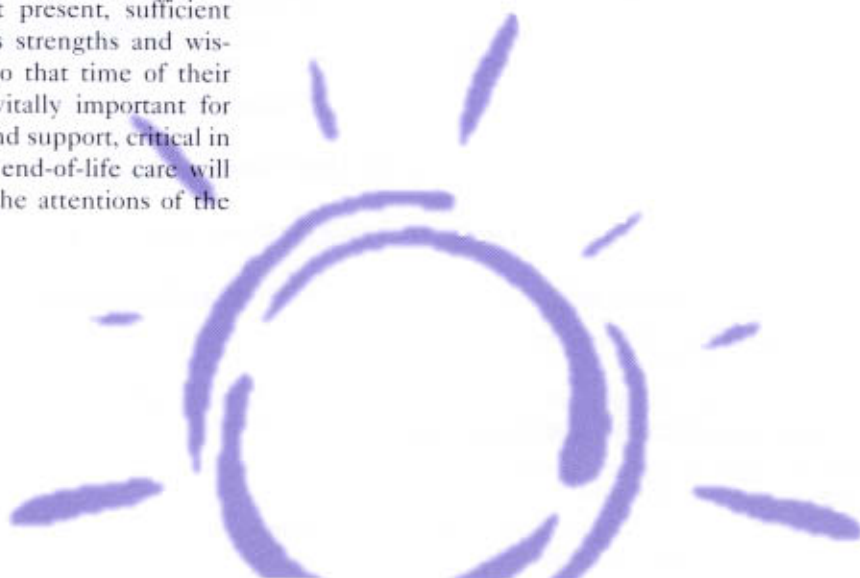
As a new millennium approaches, health care is in a profound state of transition in United States. Painful but necessary changes move us from an emphasis on young and middle-aged people with acute health care needs to a focus on an ever larger population of older people with multiple chronic conditions with attendant needs for long-term support and care at life's close. Among the plate tectonics of today's health care scene is the transition from unlimited fee-for-service financing, and health care environments defined by technology, to organized systems of pre-paid health care shaped by demands for new cost efficiencies. Perhaps the greatest transition of all is the dimming of a "doctor knows best" attitude among the general public and the rise of a patient empowerment movement which insists that health care providers respect the unique needs and preferences of patients. It is to be hoped that this movement will have a significant impact on care at the end of life.

What could possibly be a better time and place to humanize health care, and to respect an individual's wishes, than at the end of life? The twin goals of achieving continuity and coordination of care over the life span and attaining the conditions for a good death call out for a vigorous national discussion on ways and means. If ever there were a worthy object for informed and determined advocacy on behalf of older women and men, this is it.

This report is intended to sharpen a perspective on the experience and needs of older women at the end of life. In that context, it is apparent that no one profession or system of care now fully addresses the multitude of health, social, emotional and spiritual concerns that may confront women as they near the end of their lives. Nor is there, at present, sufficient understanding of the enormous strengths and wisdom that many women bring to that time of their lives. These perspectives are vitally important for shaping better systems of care and support, critical in the years ahead when age and end-of-life care will make an even larger claim on the attentions of the nation.

Many professions and social service organizations already are doing pioneering work in this arena. Good end-of-life care requires collaboration, multidisciplinary approaches, coordination among medical and social service providers and inclusion of personal, family and religious values.

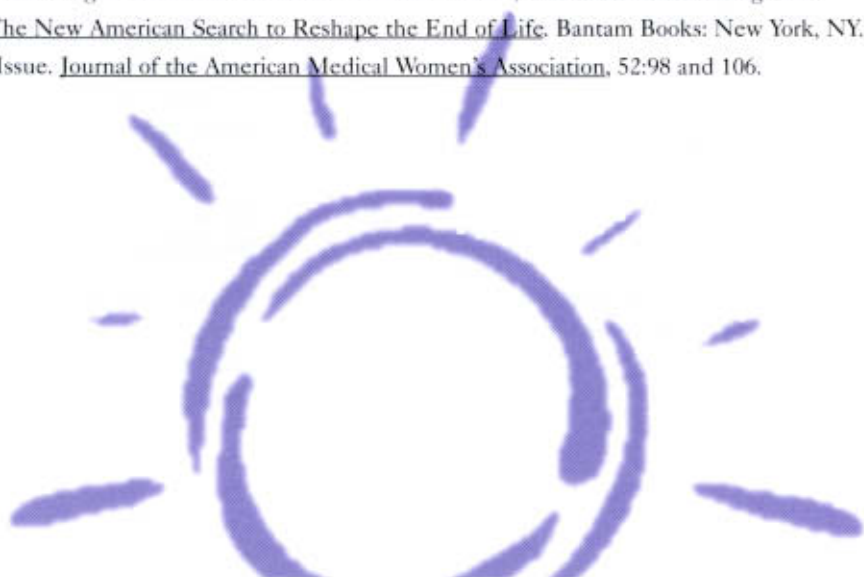
Further dissemination of information and public education must be developed and sustained. Some important beginnings have been achieved. Many organizations have begun to work together within the framework of the Robert Wood Johnson Foundation's *Last Acts* campaign. Numerous states have developed programs to address issues related to quality care at the end of life. The Institute for Healthcare Improvement has launched an extraordinary new *Breakthrough Series Collaborative* on Improving Care at the End of Life to help organizations make improvements in pain management, palliative care, advance planning and other vital areas. But as sound as these programs are, they are simply a beginning. A clear and humane vision of end-of-life care for older women is needed and it must be consistently communicated to policy makers and to the public. This will be the legacy we leave to our mothers, daughters, sisters and friends, and eventually ourselves.



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