

SELF-AWARENESS IN FAMILY CAREGIVING

A Report on the Communications Environment

**For
The Family Caregiver Self-Awareness and Empowerment Project**

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EXECUTIVE SUMMARY

BACKGROUND ON THIS PROJECT AND THIS REPORT

The National Family Caregivers Association and the National Alliance for Caregiving joined forces to conduct the Family Caregivers Self-Awareness and Empowerment Project. Funding was obtained to conduct Phase 1, the research and planning phase, of a nationwide public education program. Phase 2, to be funded separately, will comprise implementation of the plan and broad dissemination of messages.

About Family Caregiving

More than 22.4 million U.S. households are serving in family caregiving roles for persons over the age of 50, and that number will increase rapidly as the population ages, and as developments in medical science continue to extend life.¹ This expansion in family caregiving is accompanied by the “medicalization” of caregiving as our evolving health care delivery system sends hospitalized patients home sooner and sicker, with family members needing to provide many functions previously considered to be nursing.

In fact, America’s health care system is heavily dependent on the direct care family caregivers provide, especially to the aged and people with chronic diseases and disabilities. According to a study published in *Health Affairs*, caregivers’ contribution to the nation’s health care system has enormous economic value, estimated at \$196 billion annually, compared to \$32 billion for paid home care and \$83 billion spent on nursing home care.² Their services significantly reduce costs to Medicare, Medicaid, and private payers. Without this immense unpaid work force, our fragile health care financing system would be even more strained.

The nature of caregiving varies widely. Caregivers may provide care 24 hours in their homes; others offer care after work or on weekends; still others provide daily assistance to relatives in long-term care facilities, making up for sparse paid staff. The care they provide includes administering medicines and physical therapy; feeding, bathing, dressing and toileting; providing help in moving around the house; transportation; serving as an informal case manager including coordinating treatment regimens and schedules with health care professionals; and helping with financial and administrative aspects of medical care. And of course, they provide much needed emotional support that is essential to healing

or coping with disease.

The conditions their loved ones have are varied and include cancer, stroke, spina bifida, mental retardation, Alzheimer's, arthritis, mental illness, spinal cord and head injuries, multiple sclerosis and HIV/AIDS. To continue providing the tremendous service they offer, caregivers need:

- Information, support, access to services, and resources,
- Understanding and cooperation from employers, family members, friends and neighbors, health care providers, health plan administrators, their own physicians, and even strangers.
- New skills — delicate communication skills, financial management skills, time management/organizational skills, even medical-technical skills.
- Financial assistance to help with non-compensated costs for incidentals, transportation, respite care, home modifications, medical supplies, equipment and medicines.
- Someone to talk to and share experiences with.
- Someone to do an errand.
- A place to go for a change of environment and fresh perspectives.

About the Family Caregiver Self-Awareness and Empowerment Project

The overall objective of the Family Caregivers Self-Awareness and Empowerment Project is to motivate family caregivers to take actions to improve their own situation. Such actions may include enlisting another family member's help with specific tasks, arranging for formal or informal respite services, being more active in the health care interactions of their loved ones, or contacting an elected official about a caregiving policy issue. The program can motivate caregivers to action by helping them understand that caregiving is an additional role over and above their role as a spouse, child, or parent. Additionally, the program can also convey that caregivers are not alone, rather they are part of a rapidly-growing, major societal phenomenon of more than 20 million people.

The Family Caregivers Self-Awareness and Empowerment Project focuses on self-awareness as a potential trigger to empowerment and action. Many people find themselves in a caregiving role that gradually expands over time, and they do not realize or acknowledge that it has become a major role in their lives. When they do not acknowledge the role, they are less likely to take actions that protect their own physical and mental health and financial security, and consequently they are also less prepared to provide the best care possible for their loved one. Our goal is to help them acknowledge the role, and therefore become more active in taking care of themselves as well as their loved one.

About This Report

This report provides a summary of the secondary research conducted at the outset of Phase 1 to identify opportunities and gaps in information and communication — what is, and is not known — about self-awareness and empowerment in family caregiving. This research was undertaken to ensure that the project builds upon the findings of previous work and that no inadvertent duplication of effort occurs. Ultimately the report was developed to help program planners better understand the communications environment in which the project exists, and to help determine or clarify measurable objectives, audience segments, and program strategies.

METHOD

We used two approaches to conduct the research: a literature review and a communications audit.

For the literature review we searched the professional literature in related fields including gerontology, social work, psychiatry, psychology, nursing, general medicine, internal medicine, family practice, and rehabilitative medicine. We also identified unpublished literature produced by federal agencies such as the Administration on Aging and National Institute on Aging, as well non-profit organizations, foundations and professional associations.

For the communications audit we examined public education materials obtained from non-profit health advocacy organizations, private sector companies working in areas involving caregiving, and web sites of these organizations, as well. To procure materials we sent a letter and did selected telephone follow up. In response we received more than 80 individual items including brochures, manuals, fact sheets, reports, an audio tape with an accompanying manual, and one video tape. We also reviewed a variety of relevant web sites, and news and feature articles in general consumer print media. We did not review television news coverage or entertainment media due to limited time and resources. Neither did we review full-length books, because our assumption is that reading a book on a caregiving topic indicates that a caregiver has already reached a level of self-awareness that our project strives to create.

Materials obtained for the communications audit were coded into 17 topic areas relating to general information about caregiving, specific skills or tasks of caregiving, information encouraging caregivers to take care of themselves, and information that helps unacknowledged caregivers acknowledge their situation and take action on their own behalf. From this coding system we were able to analyze what was discussed — and what was not discussed — in caregiver communications materials.

FINDINGS

Findings From the Literature Review

In the last decade, the field of caregiving has grown from relative obscurity to vibrant activity.

Locus of Activity

Early research and other exploratory work were centered primarily in the gerontology and nursing professions, but more recently caregiving has received major attention from a broad range of professions and/or perspectives in the health field, including from physicians. In the last year alone significant articles have appeared in the *Journal of the American Medical Association* and in *American Family Physician*.

Topics of Activity

Early research focused on economic impact, the growth of family caregiving as a result of the evolution of the health care system, the nature of caregiving and the caregiving “career” in terms of intensity and types of care provided, demographic characteristics of caregivers and their recipients, and the use of various services.

More recent research has explored caregiver burden, stress, depression, loss of social interaction, affect on work life, and overall health affects of caregivers.

In addition, the literature reveals a focus on disease specific aspects of caregiving, especially the demands placed on those who care for patients with Alzheimer’s and cancer.

The business point-of-view has been reflected in human resource professional journals as well as business publications, with analysis of the influence of caregiving on employee turnover, decreased worker productivity, and aggregate costs to businesses.

Recently, research has focused more on the complex array of psychosocial factors related to caregiving, such as emotional conflicts created by the physical and social demands of caregiving, various aspects and measurements of caregiver burden, the various stages of caregiving (the “caregiving career”), and quality of life indicators. Many researchers in the field, however, believe that the psychosocial needs of caregivers is an area that warrants significantly more research.³ Several articles reveal that caregivers believe that the health care system fails to adequately acknowledge, support, inform and train them.

There has been little work in the area of self-acknowledgement, self-awareness, and empowerment among caregivers. Albert, Moss and Lawton, in the hope of finding information to design effective interventions, have examined the caregiving “career” to understand at what point in this career caregivers see themselves as such. Their work creates a clustering of caregivers based on the factors relating to the care they provide, and provides helpful information for this project. In addition, the work of Rhonda Montgomery and Karl Kosloski on the diversity of caregivers and the caregiving career has identified important corollaries between caregiver burden and use of services. This work, also, helps lay the foundation for this project.

Overall, the literature review revealed a focus on acknowledged, identified caregivers. **The issue of the acknowledgement versus non-acknowledgement status of caregivers, and how that might affect a willingness to take a variety of actions or utilize a variety of services has not been examined.**

One notable exception is a study conducted by AARP in November 2000 in cooperation with NFCA and NAC as initial research for this project. This nationwide survey of 4037 randomly selected adults 18 years and older located family caregivers, explored their perceptions of the term “caregiver,” and whether they identified with the term. It also explored whether they took specific actions that indicate acknowledgement of the caregiving role, such as asking for help with caregiving from others, talking to a professional about their own health, discussing caregiving issues with a supervisor, or seeking caregiving information or support groups. For the purposes of the Family Caregiver Self-Awareness and Empowerment Project, NFCA and NAC believe that an **important finding of the survey is that identifying oneself as a “caregiver” was the most significant variable in determining to what extent a respondent took the self-help or self-advocacy actions noted above.** In contrast, other factors such as age of caregiver, age of recipient, gender, race and/or ethnicity, marital status, household income, and employment status were not significant factors.

Findings From Review of Public Education and Communications Materials

We reviewed more than 80 communications items from 38 organizations. The items included brochures, articles in newsletters and magazines, fact sheets, reports, “webchures,” (brochure-type pieces posted on a web site), one audiotape with an accompanying manual, and one videotape.

Items audited were provided by organizations with a range of missions and constituencies. Some specialize in caregiving issues, such as NFCA, NAC, Well Spouse Foundation, Family Caregiver Alliance and Rosalynn Carter Institute for Human Development; others focus on specific diseases or conditions, such as Easter Seals, Multiple Sclerosis Society, and Muscular Dystrophy Association; and other organizations or federal agencies address aging issues such as AARP,

U.S. Administration on Aging, and National Institute on Aging. We reviewed myriad commercial web sites covering caregiving issues, as well.

We found that the topics most commonly conveyed were the facts and figures of caregiving. This includes how many people are caregivers, who they are in demographic terms, and what kind of care they provide. In addition, much of the material provides “how to” information on organizing the caregiving task, building skills, managing finances, and finding help.

Some organizations take a supportive, reassuring tone in their materials and remind caregivers that they are not alone, while others are more matter of fact and devoid of any emotional tone. **The large majority of material does not delve into psychosocial issues, nor does it address issues of self-awareness, self-acknowledgement or the potential value of taking certain actions to improve one’s situation.**

Findings From the Analysis of News and Feature Coverage in the Media

Coverage of caregiving as a news and feature issue in daily newspapers and consumer magazines has greatly increased in recent years, with the number of articles per year more than doubling in the last five years. An NFCA annual tracking study showed that television coverage also increased 60% from 1999 to 2000. Not only is the issue coming of age as the existence of family caregiving expands exponentially, but it also has the essential elements of a “good story” that attracts the attention of journalists. Family caregiving represents a major societal trend with plentiful data to provide a backdrop, but can be told with human interest vignettes that stir the emotions. Many articles focus on community-based services, volunteer programs and personal stories.

Most of the news and feature coverage includes discussion of the relationship between the caregiver and the care recipient, the specific caregiving tasks, the burden, and sometimes the conflicting emotions the situation can create. There is very little mention of the needs of the caregiver, or potential actions a caregiver might undertake to improve his or her own situation and to provide better care. **And, repeating the pattern of the professional literature and the public education and communications material, the notion of self-acknowledgement, self-awareness, or self-help is generally not discussed.**

CONCLUSIONS AND IMPLICATIONS

The findings of this review of the literature, communications materials and news coverage overwhelmingly indicate that the issue of self-awareness, self-acknowledgement and their relationship to empowerment of the family caregiver has not been explored. Information is plentiful on a variety of other caregiving topics, and much information has been accumulated on basic

statistical data about caregiving. For example, work has been robust in documenting demographic characteristics of caregivers and care recipients, caregiving tasks and responsibilities, caregivers' interaction with the health care system, and the economic impact of caregiving. Also, research has explored health effects of caregiving such as level of stress and its correlation to depression, anxiety and physical illness, and morbidity and mortality in general. Research has also shown that family caregiving has a negative affect on work productivity and career advancement.

The collective data show that millions of Americans are taking on the heavy burden of family caregiving without acknowledging the magnitude of those burdens on every aspect of their lives. Whether the lack of acknowledgment is part of being overwhelmed, unable to focus on one's self, denial, guilt, resistance to the "label" of caregiving, or other reasons, many caregivers go on trying to do too much, not asking for help, unaware that an entire community has formed to support them. This community of formally-organized volunteers, respite care agencies, social service agencies, home care providers, and informal networks of family, friends and neighbors can make a huge difference in the life and health of the care recipient as well as that of the caregiver. Many are available to lend a hand, yet this resource cannot be tapped until the caregiver acknowledges a need. Caregivers who do not acknowledge their situation typically do not address their own needs.

Implications for Moving Forward

A major information gap has been identified, and a great window of opportunity exists. Americans are becoming family caregivers at an ever-increasing rate, ensuring that soon most individuals will know someone who is filling a caregiving need. The topic of family caregiving is ripe for media coverage. The health care community is increasingly aware that family caregivers underpin the nation's health care delivery system, and is more interested in nurturing and supporting their role. In this environment it becomes extremely important to better understand how we can provide support to family caregivers, and to motivate them to help themselves.

To address the gap identified in these findings, the Family Caregiver Self-Awareness and Empowerment Project will further test and refine models to identify "unacknowledged" caregivers, building upon the initial information gleaned from the AARP Caregiver Identification Study released in February 2001. The model will be refined and validated to consistently identify those who are actually providing care, yet who do not exhibit any of several indications of self-acknowledgement of their role. In addition, we will explore how caregiver acknowledgement status affects caregiver actions. Do caregivers perceive any benefits or risks to identifying themselves as caregivers? Why are they more likely to take actions to help themselves and their care recipients once they have

self-identified? Is there opportunity to trigger self-identification with the goal of increasing self-help action? How, when, and why do acknowledged, aware caregivers reach their more empowered status?

The remaining work of Phase I of the Family Caregiver Self-Awareness and Empowerment project will attempt to answer some of these questions. Progress on this topic will provide critical new knowledge that will benefit caregivers in the immediate future and for generations to come.

1. INTRODUCTION

The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (the Alliance) joined together to conduct Phase I of a nationwide public education program, The Family Caregiver Self-Awareness and Empowerment Project. Both NFCA and the Alliance are leaders in the movement to better understand and assist America's family caregivers.

Purpose of This Report

NFCA and NAC conducted secondary research as the first step in program planning to maximize resources by building upon any previous relevant work, and to identify opportunities and gaps in information and communication — what is, and is not known — about self-awareness and self-actualization in family caregiving. In addition, the secondary research was designed to ensure that we do not inadvertently duplicate work that has already been done by others. This process, and the resulting report, was undertaken to help program planners better understand the communications environment in which our program will exist, and to avoid incorrect assumptions about target audience awareness, attitudes and actions. In addition, the process provides insight to help determine and/or clarify measurable objectives, audience segments, and program strategies.

Another significant reason the project staff took on this research was to inform complementary organizations about our work early in the program, in hopes of gaining their involvement and support.

This report is intended to contribute to the body of knowledge on what is known and not known about self-awareness and empowerment among family caregivers.

2. BACKGROUND ON THE FAMILY CAREGIVER SELF-AWARENESS PROJECT: The Need to Assist Family Caregivers

More than 22.4 million U.S. households are serving in family caregiving roles for persons over the age of 50, and that number will increase rapidly as the population ages, and as developments in medical science continue to extend life.⁴ A recent survey by AARP found that 34% of Americans are currently serving as family caregivers.⁵ And data from a wide variety of organizations in the aging and caregiving fields projects that an even greater percentage of Americans will become family caregivers at some point in their lives. At the same time caregiving is becoming more “medical-ized,” as our evolving health care delivery system sends hospitalized patients home sooner and sicker. In fact, America’s health care system is heavily dependent on the direct care family caregivers provide, especially to the aged and people with chronic diseases and disabilities.

The nature of caregiving varies widely. Caregivers may provide care 24 hours in their homes; others offer care after work or on weekends. The care they provide includes administering medicines, feeding, bathing, dressing and toileting; providing help in moving around the house; transportation; serving as an informal case manager including coordinating treatment regimens and schedules with health care professionals; and helping with financial and administrative aspects of medical care. And of course, they provide much needed emotional support that is essential to healing or coping with disease.

The conditions their loved ones have are varied and include: cancer, stroke, spina bifida, mental retardation, Alzheimer’s, arthritis, mental illness, spinal cord and head injuries, multiple sclerosis and HIV/AIDS. To continue providing the tremendous service they offer, we believe caregivers need:

- Information, support, access to services, and resources
- Understanding and cooperation from employers, family members, friends and neighbors, health care providers, health plan administrators, their own physicians, and even strangers
- New skills — delicate communication skills, financial management skills, time management/organizational skills, even medical-technical skills
- Financial assistance to help with non-compensated costs for incidentals, transportation, respite care, home modifications, medical supplies, equipment and medicines
- Someone to talk to and share experiences with
- Someone to do an errand
- Respite -- A chance for a change of environment and fresh perspectives

In order to obtain any, or all, of these services, family caregivers need to

recognize the changes in their own lives, acknowledge them, and adapt to them. When the recipient first needs help the needs may be minimal, such as occasional assistance with errands, financial management, or interactions with health care providers. As the recipient's medical condition or the frailties of old age progress, the caregiver may find that without recognizing it, the demands on time and resources have skyrocketed, yet he or she does not consciously acknowledge the change.

The Lack of Caregiver Self-Awareness and the Hesitancy to Seek Assistance

While there are no known studies that specifically focus on the issue of caregiver lack of self-identification, several studies have shown that family caregivers tend to feel isolated and without adequate support from family and friends. A 1998 membership survey by NFCA found that 76% of caregivers do not get consistent help from other family members. NFCA members are, for the most part, intensive level caregivers. Forty five percent felt a sense of isolation is one of the main difficulties of caregiving.⁶ Further reinforcing the feeling of isolation, a 1997 survey of 1181 callers to the Family Caregiver Alliance (FCA) in San Francisco indicated that 62% say they receive less support than they need to help with caregiving.⁷ In this same study, caregivers had been caring for an average of five years before they reached out to call the FCA information line. Similarly, an unpublished survey of NFCA members in 1999 revealed that the majority of respondents had been caregivers for more than 4 years before reaching out for help from NFCA or another organization.

Most important, however, 55% of NFCA members responding to the 1999 survey feel more empowered since inculcating NFCA's Principles of Caregiver Empowerment.⁸ This suggests that helping caregivers identify with their role and providing them with targeted messages that encourage reaching out makes a remarkable difference in how they function in their caregiving roles and their own lives. In November 2001 a survey by AARP as part of this project in fact showed that caregivers who identified with the term "caregiver" when asked if they had been a caregiver in the last year were significantly more likely than those who do not identify with the term to take positive actions such as seeking caregiving help from others, seeking information and support, talking with supervisors about caregiving, or talking with a professional about their own health, all of which are generally assumed to be actions for their own health and well-being. (This study is discussed in greater detail later in this report.)

The Family Caregiver Self-Awareness and Empowerment Project

The Family Caregiver Self-Awareness and Empowerment Project is planned as a comprehensive communication campaign aimed at family caregivers, incorporating specific tested messages and recommended interventions to

change the way family caregivers perceive themselves and behave in their role.

While an outreach/education program cannot address all the challenges family caregivers face, it can dramatically increase their ability to deal with many of them.

The overall objectives of the Family Caregiver Self-Awareness and Empowerment Project are to:

- Help family caregivers know that they are not alone; they are part of a rapidly-growing, very large group of people who can help, support, and learn from one another
- Ensure that family caregivers understand that caregiving is an **additional** role that goes over and above their traditional roles as spouse, child, or parent, so it requires **additional** support and planning
- Help family caregivers become more effective problem solvers
- For those family caregivers who **passively accept** the demands of caregiving, motivate them to **actively participate** in improving their own situation

If caregivers do not reach out for help, or have a ready-made support system, they:

- Cannot be as effective as possible in their caregiving role
- Cannot provide input to solutions addressing the societal challenges of caregiving
- Are less likely to navigate the complex and sometimes baffling health care and social service systems adeptly
- Are less likely to stand up for their own welfare and the welfare of their loved one
- Are more prone to physical and mental illnesses

Help for family caregivers does not always mean formal services. Caregivers can set up informal support networks — of relatives, friends, neighbors, others in their religious congregation, for example — to help in their caregiving tasks. It is important that caregivers understand that it is okay to ask for help from others, not a sign of weakness, selfishness, or shirking responsibility. **The Family Caregiver Self-Awareness and Empowerment Project will specifically identify messages that let caregivers know it is all right to reach out for assistance, from either informal or formal helpers.** It is the intent of this program to eventually develop messages that are motivational, relevant, and specific; test the messages with target audiences and refine them; then disseminate them widely through a variety of appropriate venues.

3. METHOD

Two main approaches were utilized in preparing this report: a literature review of published literature and non-published reports, and a communications audit. The method for both is provided below.

Literature Review: We searched for articles and reports in the area of self-awareness and self-actualization in family caregiving, or closely related areas, both published and unpublished. We defined a narrow search strategy to avoid including the significant literature on general issues of caregiving, such as the volume of family caregiving nationwide and its economic implications; demographics of caregivers and recipients; the nature of caregiving; physical and psychosocial/emotional aspects of caregiving, intensity of caregiving, caregiver burden, depression, and immune system issues, unless the articles directly referenced self-awareness or self-actualization issues in relation to the other topics. Our search strategy did, however, include articles that addressed issues of knowledge and preparedness for caregiving, coping strategies, burnout and social support, quality of life issues, stages in the “caregiving career,” social problem-solving, and caregiver reaction to caregiver education programs. We also tapped the knowledge of the many experts in caregiving on the Advisory Committee of the project, the Boards of both NFCA and NAC, and other collaborating organizations to identify research reports and articles that may be relevant.

Communications Audit

We conducted an audit of communications sources to identify what messages caregivers are receiving from various sources about their role, responsibilities, and actions to take. We examined public education materials from health advocacy organizations, news and general consumer media, and the Internet. We did not review entertainment media due to limited time and resources, although we acknowledge that entertainment media such as television programming or movies affect the communication environment as well. In addition, we did not review the many full length books published for caregivers, because our assumption is that to read a book on the topic indicates that the caregiver has already reached a level of awareness and acknowledgement that our project strives to create.

Public Education Materials

To obtain public education materials, we mailed a letter and conducted telephone follow-up requesting materials. It is important to note that we created a narrow definition of the subject matter we were requesting, to prevent receiving a large quantity of materials on caregiving in general that were not specific to our project. The outreach letter specifically requested “any material —*for family caregivers* — *that directly encourages them to be more aware of their situation, speak up for*

their own needs, and take charge of their lives” as the topic of materials we would like to review. We requested research reports, curriculum or training materials from seminars or workshops, brochures, videos, audiotapes, manuals, advertisements, or other materials. In addition to sending the letter with telephone follow-up, we posted the notice on the NFCA Web site and on the NAC list serve, and provided a brief paragraph for other caregiving organizations to post on their Web sites and publish in their newsletters.

Organizations we contacted for materials included:

Patient Education and Advocacy Organizations

- ALS Association
- Alzheimer’s Association
- American Cancer Society
- American Heart Association
- Arthritis Foundation
- Easter Seals
- Muscular Dystrophy Association
- National Multiple Sclerosis Society
- National Health Council
- National Stroke Association
- National Coalition for Cancer Survivorship
- Parkinson’s Disease Foundation
- United Cerebral Palsy

Organizations Focusing on Caregiving

- Home Care Companions
- Faith in Action
- Family Caregiver Alliance
- Children of Aging Parents
- Well Spouse
- Rosalynn Carter Institute for Human Development

Organizations Addressing the Needs of the Aging

- AARP
- National Council on Aging
- National Institute on Aging (NIH)

Organizations Addressing End of Life Issues

- Partnership for Caring
- Last Acts

Federal Government Social Service Agencies

- U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation
- Center for Medicare and Medicaid Services (formerly HCFA): Medicare and Medicaid, patient education initiatives
- U.S. Administration on Aging

Professional Associations

- American Medical Association
- American Nurses Association
- American Academy of Family Physicians
- American College of Physicians/Society of Internal Medicine
- American Geriatrics Society
- American Society on Aging
- National Association of Social Workers
- National Hospice Organization
- National Academy of Hospice and Palliative Care
- Gerontological Society of America
- Hospice Foundation of America

Selected foundations known to have an interest in elder care or caregiving issues:

- Kaiser Family Foundation
- Archstone Foundation
- Grotta Foundation
- Nemours Foundation
- Picker Institute
- Public Welfare Foundation
- Robert Wood Johnson Foundation

We also reviewed websites that include caregiving information, including:

- www.nfcacares.org (National Family Caregivers Association)
- www.caregiving.org (National Alliance for Caregiving)
- www.caregiver.org (Family Caregiver Alliance)
- www.caps4caregivers.org (Children of Aging Parents)
- www.wellspouse.org (Wellspouse Foundation)
- www.familyvoices.org (Family Voices)
- www.rsi.gsw.edu (Rosalynn Carter Institute for Human Development)
- www.alz.org (Alzheimer's Association)
- www.cancer.org (American Cancer Society)
- www.easter-seals.org (Easter Seals)
- www.mdausa.org (Muscular Dystrophy Association)
- www.nationalmssociety.org (National Multiple Sclerosis Society)
- www.aarp.org (AARP)
- www.kidshealth.org (funded by the Nemours Foundation)
- www.aoa.dhhs.gov (Administration on Aging, DHHS))
- www.alzheimers.org (National Institute on Aging, NIH)
- www.caregiversadvisorypanel.com
- www.carescout.com
- www.caregiver.com
- www.care-givers.com

- www.caregiving.com
- www.careguide.com
- www.carescout.com
- www.caregiverzone.com
- www.carethere.com
- www.familycare.com
- www.ec-online.net
- www.genet.com
- www.webofcare.com
- www.aota.org (American Occupational Therapy Association)
- www.acponline.org (American College of Physicians/American Society of Internal Medicine)
- www.ana.org (American Nurses Association)
- www.ama-assn.org (American Medical Association)
- www.aafp.org (American Academy of Family Physicians)

We also reviewed many web sites that might logically have included caregiver information because they have a significant consumer/patient focus, or their main focus is on an area that typically involves family caregiving, but we found no information especially designed for caregivers or acknowledging the caregiving role. These include:

- www.nof.org (National Osteoporosis Foundation)
- www.efa.org (Epilepsy Foundation of America)
- www.pdf.org (Parkinson's Disease Foundation)
- www.paralysis.org (Christopher Reeve Paralysis Foundation)
- www.sbaa.org (Spina Bifida Association of America)

Materials identified in the audit were coded into 17 topics areas, including:

General information:

1. Basic definitions of caregiving
2. Descriptions of caregiving tasks (including definitions or descriptions of Activities of Daily Living (ADLs) and Instrumental ADLs (IADLs))
3. Facts on the need for in-home caregiving as the population ages
4. Demographic data on caregivers
5. Trends in caregiving (gender, age, relationship to care recipient, intensity, work status, affect on work, "sandwich generation" issues, etc.)
6. Caregivers are not alone; they are part of a growing phenomenon.
7. The importance of educating oneself about the medical issues regarding the condition or disease the family member faces.
8. Additional sources for information: organizations, web sites, books, etc.

Specific skills or tasks:

9. Financial issues: paying bills, insurance coverage, Social Security and Medicare for an aging parent or spouse

10. How to hire paid home care
11. How to find and select respite care
12. How to interact with the health care team

Information that encourages caregivers to take care of themselves:

13. The importance of taking care of one's own physical health: exercise, healthy diet, regular visits to a health care provider.
14. Importance of taking care of mental and spiritual health: arrange respite, take time off, participate in enjoyable activities outside the caregiving situation.

Information that helps unacknowledged caregivers acknowledge their situation and take action on their own behalf:

15. Encouragement to acknowledge the caregiving responsibility
16. Encouragement to "get help," "take charge," or "share" the caregiving
17. Encouragement to advocate on behalf of caregivers

Media Coverage

We reviewed full text of more than 100 articles that mentioned family caregiving, obtained via Lexis-Nexis and DowJones Interactive searches of a wide variety of publications including daily and weekly newspapers nationwide, general consumer weekly and monthly magazines, and business publications. Because of the difficulty and expense of conducting a review of television news coverage (local and/or national) in any comprehensive or meaningful way, TV news coverage was not reviewed.

4. FINDINGS

Literature Review of Published and Unpublished Research on Self-Awareness in Family Caregiving

A review of published literature on family caregiving, primarily manifest in the gerontology, social sciences and nursing fields but with occasional appearances in physician journals, demonstrates a relatively recent, but rapidly increasing acknowledgement of the role of family caregivers in the health care system. Much of the earliest research conducted in early to mid-1990s sought to quantify the volume of caregiving, the economic impact of family caregiving, the growth of family caregiving as a result of health care reform and system evolution, the nature of caregiving in terms of intensity and types of care provided, the demographic characteristics of caregivers and their recipients, and the use of various services. Further research explored burden, stress, depression, loss of social interaction, and overall health effects of caregiving on caregivers. A strong consensus formed that caregiving is physically and emotionally stressful, especially in spousal caregiving among older couples, where family caregiving has been identified as an independent risk factor for morbidity and mortality.⁹ Recognizing this, the physician literature has gradually begun to place some focus on caring for the caregiver rather than studying the caregiver only as an adjunct to care for patients with chronic conditions. American Academy of Family Physicians published an article in its December 2000 journal on family caregiving that included a table of “suggested questions for assessing caregiver burden during an office visit,” based on the Zarit Burden Interview developed by Steven Zarit.¹⁰ Responding to this rising awareness among physicians, in June 2001 the American Medical Association introduced a “Caregiver Health Assessment” tool intended for physicians to offer to family caregivers when they accompany care recipients on office visits.¹¹

In addition to these general trends, considerable research has been done on a disease-specific basis; for example, on aspects of caregiving unique to Alzheimer’s, cancer, or stroke patients. At the same time, business and industry literature has documented the influence of caregiving on employee turnover, decreased worker productivity, the need for expanded benefits to accommodate caregiving, and the role of the Family and Medical Leave Act.^{12,13}

In recent years, research has begun to focus more on the complex array of psychosocial factors and conflicting emotional and physical demands that combine to comprise the caregiver’s world. Varied assessment tools have been developed to measure and analyze preparedness for caregiving, coping strategies, perceptions of caregiving roles, caregiver burden, dynamic needs of caregivers at various stages of caregiving, (i.e. the “caregiving career”), and quality of life of caregivers. Yet many researchers in the field — and caregivers themselves — believe that the psychosocial needs of caregivers is a critical area that warrants a great increase in research. As recently as 1999, Canam and

Acorn conducted a study published in *Rehabilitation Nursing*¹⁴ in which they found that while the previous decade was marked by a proliferation of research on the quality of life (QOL) of patients with various chronic illnesses in a variety of settings and treatment regimens, they believe there was minimal research (only five studies) that considered QOL of family caregivers.¹⁵ Their review article challenged researchers to do more. Similarly, The United Hospital Fund conducted a study to examine perceptions of family caregivers, and the findings indicated that caregivers believe the health care system fails to adequately acknowledge, support, inform, and train them.¹⁶ When caregivers are supported, they feel less overwhelmed and better able to cope with their expanding caregiving responsibilities.¹⁷

On the issue of self-awareness and self-identification by family caregivers and its relationship to empowerment, the published literature is minimal.

The research identified for this report concentrates on issues deemed important in clinical practice by health professionals, but few professionals or caregiving organizations have demonstrated an interest in how, when and why caregivers realize and acknowledge their changing roles. Albert, Moss, and Lawton have done significant work to examine the caregiving “career” to understand the point at which caregivers perceive themselves as such, with the stated intent of gaining a better understanding of different patterns of care to design targeted interventions.¹⁸ Their work lays a strong foundation for this project. They developed a clustering of caregivers based on the features and functions of caregiving required by the person needing care. In addition, Rhonda Montgomery and Karl Kosloski’s work on the diversity of caregivers and the path of the caregiving career has established important correlations to caregiver burden and patterns of service use.¹⁹ Montgomery’s current work in progress in categorizing caregivers into “users, seekers, and non-seekers” of respite services may provide important information for this project.

All research identified focused on acknowledged caregivers as subjects, who are relatively easy to locate through social service agencies, home care providers, and patient education/advocacy organizations. The failure to focus on unacknowledged caregivers or on the issue of self-awareness versus awareness in general may be based on assumptions that this project challenges. For example, we will explore the following concepts that may run counter to established assumptions:

- Caregivers do not automatically identify themselves as such when they take on caregiving responsibilities, even when caregiver burden is high. (As noted previously, most caregivers do *not* acknowledge their role and reach out for help until they have been providing care for at least 4 years.)
- In addition to acknowledged caregivers, unacknowledged caregivers may also be ready or likely to respond to interventions. (Anecdotal evidence of several consumer organizations in the caregiving field shows that

unacknowledged caregivers can be identified, reached, and motivated to action with carefully developed messages and materials.)

Lack of awareness of the issue of “unacknowledged” caregivers — who while they may not recognize the magnitude of their role are nonetheless very critical to the delivery of care and support for the patient — may in fact be the primary reason that no prior research has been implemented on this topic. In addition, another reason may be that much of the research does not take the caregiver point of view; rather, it primarily investigates caregivers as adjuncts to the health care delivery system.

In addition to research in peer-reviewed professional journals, organizations with an interest in caregiving have explored a variety of the more complex aspects of caregiving with surveys, focus group studies, and secondary research. One such survey of caregivers, conducted for Partnership for Solutions, a program of The Robert Wood Johnson Foundation and Johns Hopkins University, measured the level of involvement of caregivers in the day-to-day aspects of care management and coordination with health care providers in great detail, but did not include measures of the caregivers’ attitudes, reactions, or acknowledgement of their responsibilities.²⁰ Another recent survey by Kaiser Family Foundation (KFF) and *Family Circle* magazine probed attitudes of caregivers caring for a parent, and revealed that a large majority of these caregivers find it emotionally fulfilling, with 96% saying they feel “loving,” 90% feel “appreciated,” and 84% “proud.”²¹ But again, the KFF survey sample included anyone who has a parent over 65, many with a very low burden of care, and did not address the issues of those who may be providing a high level of care but do not recognize it as such.

One notable exception to the lack of examining the self-acknowledgement element is a survey conducted by AARP in November 2000 in cooperation with NFCA and NAC as initial research for this project. The study explored perceptions of the term “caregiver,” whether caregivers identified with the term, and whether they engaged in specific self-help or self-advocacy actions, such as reading about caregiving, asking for help with caregiving, arranging for community services, discussing caregiving with a supervisor, or joining a caregiving organization or support group. Remarkably, 15% of the survey respondents did not identify that they were caregivers when first asked, but when prompted with a battery of questions on caregiving tasks, they revealed themselves to be actual caregivers. Most notable, however, is that **identifying oneself with the term “caregiver” was the most significant variable in determining to what extent a respondent took self-help actions, such as reading about caregiving, asking for help with caregiving, talking to a professional about one’s own health, arranging for services, discussing caregiving with a supervisor, seeking information, or joining a support group or caregiver organization.** Other variables such as age of caregiver, age of recipient, gender, race and ethnicity, marital status, household income, and employment status did not consistently correlate to significant differences in

taking such action as did self-identification status. The 19% of respondents who identified with the term “caregiver” were significantly more likely to take proactive steps to adapt to and improve their own situations than those who did not identify with the term. Details are shown in the table below.

Action taken	n= 1714*		
	Self Identified “Caregivers” (19%)	“Actual” Caregivers** (15%)	“Questionable Caregivers”*** (10%)
Talked informally to others about caregiving	76%	64%	50%
Talked to a health professional about the care recipient	63%	38%	38%
Read about caregiving	54%	40%	37%
Asked for help with caregiving	42%	30%	24%
Talked to a health professional about your own health	38%	19%	17%
Arranged for community services	39%	19%	15%
Discussed caregiving with supervisor (Employed caregivers only. N=1190)	34%	10%	22%
Used a web site to look for caregiving information	19%	13%	10%
Joined caregiver organization or support group	15%	8%	8%
Contacted elected official about caregiving	14%	6%	6%

Source: AARP Caregiver Identification Study, February 2001.

* Base: Respondents who answered “yes” to unaided and aided questions asked to determine if they are providing caregiving.

** The AARP survey designated as “actual caregivers” those who did **not** identify with the term “caregiver” but responded “yes” when asked if they provide specific caregiving activities.

*** The AARP survey designated as “questionable caregivers” those who responded “yes” when asked if they are “a caregiver” but “no” when asked if they provide specific, basic caregiving activities.

Prior to the initiation of the NFCA/NAC Family Caregiver Self-Awareness and Empowerment Project, it appears that there has been little work to formally explore the events, circumstances, processes, or character traits that might trigger self-awareness of the new roles and responsibilities, and what affect an enhanced self-awareness may or may not have on the caregiver’s feeling of self-efficacy and empowerment, quality and longevity of caregiving for the recipient, and quality of life for the caregiver. This is not surprising, given the difficulty of identifying those who have not acknowledged to themselves that they are in some way or another a “caregiver” because of the tasks they perform, regardless of the terminology used. Beyond the difficulty of recruiting “unacknowledged” subjects for study, compounding the

likelihood that this aspect of caregiving has not been explored is the relatively new nature of the concept.

While the extant research among acknowledged caregivers continues to make vital contributions to the field and illuminates many important aspects of caregiving and the caregiving relationship, our findings indicate that more study is warranted to directly address the relative importance of self-awareness and self-acknowledgement, and feelings of empowerment as critical factors in the caregiving function.

Communications Materials

We reviewed more than 80 discrete items produced by 38 organizations, all designed to communicate with or educate caregivers or caregiving thought leaders on various aspects of caregiving. (See the Appendix for a table of all materials reviewed.) These included brochures, booklets, fact sheets, reports, newsletters, “webchures,” or brochure-format pieces on web sites, articles in magazines or specialized publications developed especially for caregivers or on the topic of aging and eldercare, one audiotape with an accompanying manual, and one videotape. The magazine articles in caregiving and eldercare newsletters and magazines we reviewed as communications pieces targeted to caregivers, not as general media items that are reviewed in the next section.

Topics of Interest, and Non-Topics:

A large majority of communications materials we reviewed did *not* address issues of self-awareness, acknowledgement, or recognition of changing roles and additional burdens of caregiving. Relatively few materials directly addressed these issues, and those that did were produced by organizations solely devoted to the caregiver, to chronic conditions that place high demands on caregivers, or to issues of the aging. The messages and materials that overtly urge caregivers to acknowledge the burden of their situation and take care of themselves were produced by:

- **NFCA:** “Share the Caring,” “Choosing to Take Charge of Your Life,” “Defining the Help You Need,” and regular articles and editorials in the newsletter, *Take Care*
- **National Alliance for Caregiving:** “Caregiving Tips” web site brochure
- **Well Spouse Foundation:** Membership brochure (no title) and regular articles and editorials in the newsletter, *Mainstay*
- **Caregiver Assistance Network of Catholic Social Services of Cincinnati:** “Caregiver Assistance Network: A Helping Hand for You, the Caregiver” and fact sheet, “Support Groups for Family Caregivers”
- **Easter Seals:** “Are You a Caregiver?”
- **National Multiple Sclerosis Society:** “A Guide for Caregivers”

- **National Coalition for Cancer Survivorship:** “Caring for the Caregiver” (audiotape and manual)
- **Muscular Dystrophy Association:** “Taking Time Out for the Rest of Your Life”
- **Administration on Aging:** “Because We Care: A Guide for People Who Care”
- **AARP:** “Caregiving: Managing Stress When Giving Care” and “Basic Survival Tips for New Caregivers” (video)
- **“dot.com” companies** that have emerged to capitalize upon the new marketing opportunity this population presents.

The acknowledgement issue is most commonly raised by providing definitions of caregiving and descriptions of caregiving tasks (including listings of IADLs and ADLs) as a means of helping people identify themselves as caregivers. In these materials the tone tends to be sympathetic, supportive and encouraging. Further, in the materials of those organizations mentioned above that attend to the issues of self-awareness and emotional needs, the tone of sympathy, support and encouragement for caregivers infuses all communications. In short, it is apparent that among these organizations a general philosophy of recognizing and placing high value on caregivers’ contributions permeates all outreach efforts. However, the philosophy does not extend to hone in on self-awareness and empowerment as critical issues for caregivers, again, most likely because these issues have not been previously raised and explored extensively in the caregiving community. Thus, it can be said that among most caregiver-focused organizations, sympathy and emotional support are high priority, but self-awareness, self-recognition and a sense of empowerment are not yet on the radar screen.

Topics Most Commonly Conveyed: Facts and Figures

Reflecting the pattern of most research on caregiving, a majority of communications materials convey general information that codifies and quantifies caregiving but does not delve into psychosocial issues. The materials provide basic definitions and descriptions of caregiving (including listings of IADLs and ADLs), data on the “aging of America” trend and the growing need for family caregiving as the health care delivery system and the long-term care industry evolve, and trend analysis on age, gender, relationship work status, work productivity and economic issues of caregiving. Organizations such as Family Caregiver Alliance, Family Voices, Children of Aging Parents, and Alzheimer’s Association provide a wealth of information on organizing the caregiving task and the home environment, managing the financial aspects of caregiving, building specific caregiving skills, planning ahead for changes in the care recipient’s health status, the need to advocate for more societal support, and where to find outside help, information and referrals. This information is provided in a straight forward and matter of fact way, without a personal or emotionally supportive tone. Yet several of the items reviewed mention the

increasing prevalence of caregiving with statistics on the large number of caregivers nationwide, reassuring readers that they “are not alone.”

Media: News and Feature Coverage

Coverage of caregiving as a news or feature issue in daily newspapers and consumer magazines seems to have increased in recent years, with the number of articles appearing in the last five years more than double the number in the previous five years.²² Continuing the trend, coverage in major television and media outlets increased 60% in the first 8 months of 2000 alone compared to the previous year, according to a media tracking study commissioned annually by NFCA.²³ This is not surprising, as journalists discover that caregiving has all the elements of a “good story” that meets their criteria to warrant coverage: It represents a major societal trend supported by abundant, rigorous data; it can be reported with personal vignettes that stir the emotions; and the pathos it evokes can be balanced with universally appealing concepts of the triumph of the human spirit or unconditional love. Further, the topic of caregiving feeds into the nation’s fascination with Baby Boomers and the massive demographic shift their aging process brings.

Most articles began with an account of one person’s caregiving story, then branched out to report on the experience of additional caregivers. Several articles used a “day in the life” chronicling technique. In each case, the articles report primarily on the larger trend data and the broader issues in the realms of health care, work, family relationships, and society as a whole. Several articles take a “how to” approach, serving more as education feature articles than news reports. One such article in *The Pittsburgh Post-Gazette* borders on advocacy, urging readers to make “informed choices” to “decide what level of caregiving is right for you and your loved ones.”²⁴ These types of articles usually include a table with a brief list of resources, contact numbers and email addresses.

Another common approach is to report on a community program as the central theme of the story, as in the case of *The Cincinnati Post* article²⁵ reporting on the Catholic Social Services Caregiver Assistance Network in the greater Cincinnati area. These reports on community-based efforts typically intersperse personal vignettes throughout the article to bring the story to life.

Reflecting the increasing prevalence of caregiving, some articles are autobiographical, with the reporter sharing personal experience of caring for a loved one. For example, an article in *The Washington Post* revealed that a short-term experience caring for his injured wife dramatically changed the reporter’s priorities and perspective on caregiving.²⁶

In almost all news and feature coverage, topics include the relationship between the caregiver and the cared-for, the specific caregiving tasks, the burden, and the conflicting emotions it creates. There is very little talk about the needs of the

caregiver, and no mention in the articles reviewed on the nuances of caregivers motivations and feelings as they reach a point of realizing how much their lives have changed. **As in the research literature and the public education and communications materials, the notion of self-acknowledgement or self-awareness among caregivers is absent in the news coverage.**

5. CONCLUSIONS AND IMPLICATIONS

The findings of this review of literature, communications materials and news coverage of caregiving and caregivers overwhelmingly indicate that the issue of self-awareness, self-acknowledgement and their relative meaning to the empowerment of the caregiver has not been explored. Information abounds on a host of related issues, and a significant body of knowledge has accumulated on basic statistical information about caregiving. For example, work has been robust on the following areas:

- Demographic characteristics of caregivers and care recipients
- Caregiving tasks and responsibilities
- Caregivers' interaction with health care system
- Economic impact of caregiving
- Health effects of caregiving: level of stress and its correlation to depression, anxiety, and physical illness; morbidity and mortality in general
- Effect on work productivity for the employer and career advancement for the employee
- Effective models for caregiver education

However, the findings of this review confirm that millions are taking on the heavy burdens of caregiving without acknowledging the magnitude of those burdens on every aspect of their lives. Even those organizations and individuals who seek either to serve caregivers or to capitalize upon the existence of this new population are slow to recognize the inherent conflict so many caregivers face. This may occur because the burden is minor or occasional in the early stages of caregiving, and the caregiver perceives that "this is what a good daughter/son/spouse should do." As the caregiving burden progresses over time, however, they may not realize how significantly it has affected their lives.

Whether stymied by being overwhelmed, fear of sinking further into over-commitment, denial, guilt, or resistance to the "label" of caregiving, many caregivers go on trying to do too much, not asking for help, unaware that an entire community has formed to support them. This community comprises formally-organized networks of volunteers, social service agencies, home care providers, respite care agencies, and friends, family members and neighbors who will lend a hand when given a specific job to do. Yet the community of

caregiver support cannot be tapped until the caregiver acknowledges his or her need. And caregivers who do not acknowledge their situation typically do not address their own needs.

Thus, a great window of opportunity exists. While new research in various aspects of caregiving is in early development stages, while the caregiving topic is ripe for continued and expanding media coverage, and while an increasing number of organizations reach out to caregivers every day, we can all strive to learn more — and convey our learnings to the field and to caregivers — about the role acknowledgement plays in ensuring the best quality of life for the caregiver and the care recipient.

Moving Forward: To address the gap identified in these findings, the Family Caregiver Self-Awareness and Empowerment Project will further test and refine models to identify “unacknowledged” caregivers, building upon the initial information gleaned from the AARP Caregiver Identification Study of February 2001. The model will be refined and validated to consistently identify those who are actually providing care, yet who do not exhibit any of several indications of self-acknowledgement of their role. In addition, we will explore how caregiver acknowledgement status affects caregiver actions. Do caregivers perceive any benefits or risks to identifying themselves as caregivers? Why are they more likely to take actions to help themselves and their care recipients once they have self-identified? Is there opportunity to trigger self-identification with the goal of increasing self-help action? How, when, and why do acknowledged, aware caregivers reach their more empowered status?

Once we have gathered information to answer these and other questions, we will develop potential messages to motivate unacknowledged people to acknowledge, and test message concepts among unacknowledged caregivers to determine which ones are most effective in changing attitudes and behavior. In addition, we will explore what venues reach these individuals most efficiently. We will explore both formal media channels and informal word-of-mouth communications venues, as well. When we have completed the research to refine messages and delivery channels, we will fully implement a communications campaign to reach unacknowledged caregivers.

Progress on this topic will provide critical new knowledge that will benefit caregivers in the immediate future and for generations to come.

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