

6708

EXECUTIVE SUMMARY

**Disease and Injury Prevention and Health
Promotion in Elder Care:
Needs and Opportunities as Perceived by
Elder Care Providers, the Elderly, and their
Families**

Contract No. 200-96-0598, Task 7

submitted to:

Hospital Infections Program
National Center for Infectious Diseases
Centers for Disease Control and Prevention

by:

Macro International Inc.
3 Corporate Square Suite 370
Atlanta, GA 30329
404-321-3211

November 30, 1997

MACRO
INTERNATIONAL INC.

Executive Summary

I. Background

The aging of the American population poses numerous challenges to the elderly, their family members, and the providers who care for them. As sources of preventive services and information on a wide range of health and safety issues, public health agencies can support families and providers as they seek ways to maintain the health and well-being of the elderly in our society.

This focus group study sought the opinions of elderly men and women, spouses and other family members who care for them, and non-medically trained paraprofessionals who work with the elderly and their families.

II. Purpose of This Study

The purpose of this research was to identify interests and concerns of the elderly, their families, and elder care providers in selected areas of health and safety to help inform the development of a handbook delineating CDC policies and recommendations in disease prevention and health promotion in elder care settings. Key areas addressed by the study include:

- topics of interest in preventing disease and injury and promoting healthy behaviors
- the role of public health agencies in encouraging health and safety through consultation, inspection, regulation, or similar mechanisms
- opportunities to educate the elderly, their families, and elder care providers in disease prevention and health promotion, including issues not specific to the elder care setting (e.g., violence and abuse prevention, nutrition, etc.) via outreach through the elder care setting
- opportunities for direct delivery of prevention and public health services (e.g., immunizations, dental check-ups, vision and hearing screenings, etc.) through elder care settings, especially for the elderly in medically underserved areas of the population.

III. Methodology

Eight focus groups were conducted in Atlanta, Georgia, and in Floyd County, a rural area in the northwest part of the state. Focus group participants included the elderly themselves, family members (spouses or companions of the same generation as well as children or younger relatives), and providers. In each case, participants were those who either lived independently or cared for elderly relatives or clients who were still ambulatory. This distinction was made because the health and safety and caregiving issues for non-institutionalized elderly (and their families and caregivers) are quite different.

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Each focus group discussion followed a series of questions designed to elicit information on key sources of health and safety information, concerns in these areas, reactions to current or proposed materials, and the potential role of public health agencies.

Focus group research is a qualitative research method that is often used in the early stages of broader research or materials development projects. While focus group results cannot be generalized to larger populations, they do suggest lines of inquiry and initial reactions that can guide future research or products. Because participants answer questions in a group setting, the moderator can probe for additional reactions and insights from the group that would not be available through other data collection techniques, such as individual interviews or surveys.

IV. Findings

A. Elderly

To whom do the elderly turn for health and safety advice?

- **The main sources of health and safety information for elderly focus group participants were their private physicians.** Participants noted, however, that their physicians did not always have time to answer all their questions. Those who had to consult **specialists** worried that their care was not necessarily coordinated by any particular physician. In some cases, participants thought their physicians were overly concerned about health and safety issues.
- **Pharmacists and pharmacies** constituted another important source of information -both the pharmacists as individuals, and the materials available in the pharmacy setting. Although participants praised the useful information available in pharmacy printouts that accompanied their medications, they complained about the small print size and medical jargon in these materials. **Family members** — especially those trained in the medical field — were another often-cited source of information.
- For the elderly patient, the most important features of any interaction with providers were the providers' **knowledge** of the elderly patient's overall condition, and the elderly patient's **trust** that the provider would thus manage his or her condition effectively.

What are the elderly's main health and safety concerns?

Health and safety concerns included:

- falls
- medications and their side effects
- warning signs of Alzheimer's disease, heart attacks, and cancer
- safetyproofing the home
- diet and nutrition, especially regarding diabetes and high blood pressure
- healthier cooking techniques
- safe exercise
- insurance issues — especially how to avoid “scams.”

How can health and safety information be disseminated to the elderly?

- **Transportation barriers and unfamiliar surrounding would keep most of the elderly away from health and safety classes.** Mobile vans and health fairs are considered too public a setting for asking personal questions about health. With one exception, the elderly participants in these focus groups were not aware of the health department's functions, nor did they view such agencies as potential sources of useful information.
- **Videos and large-font printed materials**, large enough to handle with arthritic hands, were recommended as suitable mechanisms for transmitting health and safety information.

B. Elderly Caring for Elderly: Spouses and Companions

To whom do spouses/companions turn for health and safety advice?

- Spouses/companions turn to their **family members' physicians and nurses and other family members.** **Support groups** were especially valued sources of information (as well as support) among those caring for a spouse with Alzheimer's disease.

What are spouses'/companions' main health and safety concerns?

- Half the participants were caring for someone with **Alzheimer's disease.** The confusion and decline associated with that disease were paramount concerns for spouses, as were the disease's consequences in terms of safety, independence, and communication.

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- Information on the warning signs of Alzheimer's would have been helpful, to give families time to prepare emotionally and financially.
- **Falls, medications, and financing care in the future** were other concerns.
- **Spouses/companions were also concerned about their own health**, particularly nutrition, exercise, preventing injuries (especially from lifting or moving their spouse or companion), and maintaining their own mental/emotional health.

How can health and safety information be disseminated to spouses/companions?

- Spouses and companions were more receptive than others to the idea of attending classes or seminars on health and safety topics.
- A video and/or manual specifically designed for this population would be well-received. Suggestions included a video following a "This Old House" format, showing how to make each room in the house or apartment safer for an elderly person.
- Spouses/companions were unfamiliar with health departments and their resources.

C. **Family Members (children, grandchildren, nieces, nephews, etc.)**

To whom do the family members turn for health and safety advice?

- Family members turned to **private physicians** caring for the elderly family member, as well as to the **local hospital's social work department** (for referrals to other services).

What are family members main health and safety concerns?

- Concerns include the elderly family member's **diet, nutrition, and safety (particularly cooking and driving)**.
- Family members would like more information on:
- **lifting or moving** the elderly family member
- **communicating effectively** with an elderly family member when family roles are reversed

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- **convincing elderly family members to ask for help**
- discussing **driving** with family members who are at risk of endangering themselves or others
- the medical management of **severe pain**
- **medication** interactions and side effects.

How can health and safety information be disseminated to family members?

- Family members suggested **videos and local cable television** as suitable channels of information.
- Some recommended a “**survival kit**,” perhaps prepared by the health department, with a variety of useful referral telephone numbers, checklists and tips for caring for an elderly relative.
- **Health departments were not mentioned** as a potential resource or source of information.
- Family members noted that in publications for or about the elderly, **the elderly should be portrayed in a positive light** — as active, alert people, rather than as infirm and feeble.

D. Elder Care Providers

To whom do providers turn for health and safety advice?

- Providers who work for an agency turn to their immediate supervisors and/or colleagues; providers who are self-employed turn to colleagues (especially those with a medical background) and/or reference books.

What are providers’ main health and safety concerns?

Providers’ concerns include:

- dealing with the behavior of elderly clients, especially combative/belligerent behavior and mood swings
- when (and when not) to seek emergency care
- moving clients after they have fallen

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- lifting/moving clients safely.

Concerns often raised by their clients' family members include:

- falls
- driving

Topics that should be addressed in training include:

- experiencing the world through the client's eyes (wearing cotton balls in one's ears, smearing Vaseline on eyeglasses, moving around in a wheelchair) to gain an understanding of and empathy for what clients experience
- interacting with clients
- helping clients and family members safetyproof the home
- food safety
- preparing for extreme heat or cold.

How can health and safety information be disseminated to providers?

- Videos and in-service training sessions would be the most accessible formats for providers. (Few had received formal training to work with the elderly.)
- Videos and training situations should depict real situations that providers might encounter — combative behavior, awkward lifting or moving of a client, frustration.

V. Conclusions/Recommendations

The elderly, their relatives, and the providers who care for and advise them are eager for current, practical information on health and safety. No comprehensive resource currently exists, yet one is greatly needed and, according to participants, greatly desired.

A modular format could be developed, with some common sections on basic health and safety information and others geared to the different needs of the elderly and their caregivers. Although no single document could address the myriad specific questions that the elderly and their caregivers might have, a compendium could address major categories and suggest other organizations to turn to for more specific information.

In terms of format, large print, easy access to information, and clear graphics were common suggestions across all four groups. However, classes or seminars on health and safety information were well received by only those focus group participants caring for the elderly, not by the elderly

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themselves. For caregivers, classes on caring for the elderly and handling difficult issues were most desired.

Prevention services, in particular public health services such as flu shots, pneumonia shots, and TB skin tests were considered important and worthwhile to provide to the elderly. However, screening services, such as blood pressure, cholesterol, and diabetes, were considered by most elderly, their family members, and their caregivers as most appropriately and adequately provided by private physicians. Yet, offering such services to disadvantaged elderly and those without transportation was still considered an important function and service.

The lack of awareness of public health's scope and potential usefulness as a source of information was an unfortunate theme in these focus groups — one that has been documented in other types of research as well. However, research on the general public's attitudes towards public health also has revealed an encouraging silver lining. In general, the public's lack of awareness about public health agencies seems rooted in a lack of exposure, rather than in hostility or negative experiences. The opportunity to positively influence the public's views about public health is largely untapped.

The effort to consolidate useful, relevant information on the health and safety of the elderly — an issue that affects almost every American family — will be tremendously appreciated and represents an opportunity for CDC and its partners at the state and local levels to raise awareness of public health's continuing role in the lives of every American.

FINAL REPORT

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I. Introduction

“Many years ago, there was always a spinster sister, a devoted daughter, or a daughter-in-law who took responsibility for caring for aging parents. It really wasn ’t a problem then . . . but over time families became more spread out, children moved away, and oldpeople were simply put into nursing homes . . . But nowadays nursing homes are so expensive and it’s hard to find a good one, so most older people would rather stay at home, live on their own . . . so now what do we do? ”

Daughter who cares for her aging mother

The scenario described above is the current reality of approximately 34 million Americans (ages 65 and older) as the twenty-first century approaches.¹ Concurrent with the “greying” of the U.S. population has been a steady demand for personal care services for the elderly. In response to the increasing cost of skilled nursing facilities and growing concerns about the future of Medicare, there has been a marked increase in the use of personal care services for the elderly — many considering such options to be more personal and humane than their more costly alternatives. In particular demand is assistance in maintaining hygiene and performing routine personal care chores as well as information on common diseases and conditions of the elderly. The use of personal health aides to assist with housekeeping and hygiene has become increasingly popular along with other paraprofessional services such as adult day care services, respite services, and therapeutic recreational activities.

While such services offer the elderly and their families cost-effective alternatives to nursing homes, many of the professionals delivering these services are not health care professionals and therefore may lack the necessary training or information in basic health issues and disease and injury prevention. In addition, the growing numbers of elderly who choose to care for themselves and the increasing numbers of family members taking on this responsibility highlight the importance of providing Americans with the necessary skills and information to maintain health status and prevent disease, illness, and injury.

As the nation’s premier public health agency, the Centers for Disease Control and Prevention (CDC) is well positioned to respond to the needs of Americans as they grow older. Over the past few years, the agency has received numerous inquiries from elder care professionals requesting both basic health information and more specific information on reducing the spread of infectious diseases and the incidence of drug resistance. In response to these inquiries, CDC has accelerated its efforts to provide useful, timely, and practical information on preserving the health of an aging America.

¹ American Association of Retired Persons, *A Profile of Older Americans*, 1996, Wash&on, D.C.

II. Purpose of This Study

The Hospital Infection Program within the National Center for Infectious Diseases contracted with Macro International Inc. under the CDC Policy Assessment Contract (200-96-0598/07) to carry out a study of “Disease and Injury Prevention and Health Promotion in Elder Care: Needs and Opportunities as Perceived by Elder Care Providers, the Elderly Themselves, and Their Families.”

The purpose of this study was to identify interests and concerns of the elderly, their families, and elder care providers in selected areas of health and safety to help inform the development of a handbook delineating CDC policies and recommendations in disease prevention and health promotion in elder care settings. Key areas addressed by the study include:

- topics of interest in preventing disease and injury and promoting healthy behaviors
- the role of public health agencies and licensing and regulatory agencies in encouraging health and safety through consultation, inspection, regulation, or other mechanisms
- opportunities to educate the elderly, their families, and elder care providers in disease prevention and health promotion, including issues not specific to the elder care setting (e.g., violence and abuse prevention, nutrition, etc.) via outreach through the elder care setting
- opportunities for direct delivery of prevention and public health services (e.g., immunizations, dental check-ups, vision and hearing screenings, etc.) through elder care settings, especially for the elderly in medically underserved areas of the population.

In each of these areas, study participants were asked to consider the following:

- At what level of existing knowledge or understanding of health and safety issues should messages be written?
- How should messages be structured?
- What type of format would be most useful?
- What are the barriers to implementing recommended health and safety messages?

III. Methodology

A. Focus Groups: Strengths and Caveats

This study examined the views of the elderly, their families, and elder care providers, all of whom represent “consumers” of health and safety information for people over the age of 55. Exploring their views and concerns through a group discussion format offered an opportunity to conduct qualitative research in this growing field of interest.

Focus group discussions were chosen as the most appropriate research technique for this study because they are ideally suited to explore and probe a wide variety of topics and inform the early stages of a research project. Focus groups have been a standard methodology for consumer products research, where they are used to gain insights into consumer preferences regarding a wide variety of products and their specific attributes.

The interactive discussion promoted by focus group methodology is often an ideal way to ask straightforward questions and to receive “real life” answers. This interaction among participants often reveals much more information than other data collection techniques, such as surveys or one-on-one interviews. In addition, a skilled moderator can follow up on or probe certain tangents or views that were unanticipated in the design of the discussion group guide, often yielding new information and/or additional nuances of existing information.

Despite these advantages, focus group methodology is not without limitations. Findings from focus group discussions are neither quantitative nor generalizable to the population as a whole. Focus group findings are suggestive, not definitive, and should be used to enrich understanding of an issue rather than to unequivocally support a certain position. In addition, although trends and commonalities are important in focus groups, “outliers” and more solitary voices also have weight. In fact, more uncommon views are often the most revealing and significant in focus group research. Within these constraints, however, focus groups can offer researchers valuable insights that can be integrated into program plans or reveal new lines of inquiry for future research efforts.

B. Recruitment of Focus Group Participants

The target audiences for this focus group project consisted of the following:

- elderly (55 years and older)
- elderly who care for elderly spouses or companions
- elder care providers (non-medical professionals who provide care to the elderly)
- family members who care for an elderly relative.

In an effort to gain geographic and socioeconomic diversity, focus groups were held in two settings: Atlanta (urban setting) and the rural areas surrounding Floyd County (Rome, Georgia).

III. Methodology

Flyers describing the focus groups were distributed to a variety of local public and private agencies and organizations in both Atlanta and the Floyd County area. Flyers were also posted in community centers, apartment complexes, and other recreational and residential settings where older people either live or congregate. The vast majority of the elderly and family member participants were recruited in this way. Participants in the elderly and family member groups were much easier to recruit than elderly who care for a spouse or companion. These potential respondents were reluctant to participate because they often were the sole caretakers for their spouses or companions, and could not leave them unattended.

Elder care providers were recruited by disseminating flyers to both public and private agencies that provide services to the elderly such as respite, recreational activities, personal care services, home health services, and adult day care. In an effort to recruit providers who are not professionally associated with a particular agency, flyers were distributed to local churches, community centers, and other sites where older people either gather or receive services.

As stated on the flyer, people who were interested in participating in one of the focus groups were asked to call Macro to register for a group. Upon calling Macro, prospective participants were asked to complete a brief telephone interview for screening purposes to ensure that callers would be assigned to the most appropriate group. Copies of the flyers and screening interview forms can be found in Appendices A and B, respectively.

C. Conducting the Focus Groups

A total of eight focus groups were held in Atlanta and Floyd County between August and November 1997, with the following types of participants:

	Urban/Suburban	Rural
Elderly	2 ²	1
Elderly Spouses	1	0
Family Members	1	1
Elder Care Providers	1	1

Only one person attended the elderly spouses/companion group held in Floyd County. However, this participant was interviewed and her comments incorporated into the discussion that follows. Between 5 and 11 participants attended the other group discussions.

² Due to the large turnout (11 people) of participants for this group, they were divided into two separate groups of five and six to make the discussion more manageable.

III. Methodology

The location of the focus group discussions varied, depending on what was most convenient for participants. In general, the majority of focus groups for the elderly participants took place in the community, at either a local recreation center or an apartment complex within walking or driving distance to most attendees. However, in Atlanta, the focus group for family members and providers was held in the conference room of Macro's Atlanta office. All of the focus groups held in Floyd County were convened at the local senior recreation center, a well-known site in the community.

Focus group participants received a \$25 stipend for attending the group as well as brochures, booklets, and flyers addressing a wide range of health and safety topics pertinent to the elderly and those who care for them. These materials were published by a number of both public and private agencies such as the National Institutes of Health, the Health Care Financing Administration, the American Red Cross, the American Association of Retired Persons, the American Cancer Society, and the Administration on Aging. Financial assistance with transportation was also provided or arranged for elderly participants who could not drive.

The focus group discussions were guided by a moderator who closely followed a pre-developed moderator's guide aimed at addressing several main topics of interest as well as probing for any tangential issues or views that may arise. A separate discussion guide was developed for each of the four groups, copies of which can be found in Appendix C.

In an effort ensure that health and safety information is as useful and relevant as possible, focus group participants were asked to spend the final 15 minutes of the discussion thinking about the format (size, shape, color, etc.) most suitable and useful for reaching the elderly population. Below is a description of the materials reviewed.

Foundations of Caregiving, American Red Cross, July 1993. This 1.5 lbs., 8.5" x 11", 560-page, colorful, glossy-covered handbook was originally designed as an accompaniment to an American Red Cross course for caregivers of the aging, young, and infirm. The book provides very detailed descriptions on providing specific services such as transferring patients, food preparation, and proper bathing. Colorful diagrams and photos accompany these descriptions and can be found on the margins of almost every page of the book.

Resource Directory for Older People, National Institute on Aging, March 1996. This 274-page, black-and-white, spiral-bound, 6.5" x 9" directory provides the names, addresses, and telephone numbers of over 200 public and private agencies offering health and information services to the elderly.

Talking with Your Doctor: A Guide for Older People, National Institute on Aging, December 1994. This 29-page, 8.5" x 11", glossy-covered booklet provides readers with various strategies for improving communications with their providers. Important information is bulleted in the margins of each page, the print is large (14- to, 16- point font),

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and lively caricatures, depicting the do's and don'ts of effective communication, accompany many important passages.

Talking with Your Doctor, American Cancer Society, 1996. This 9" x 3.5" colored pamphlet was designed to assist cancer patients in effectively communicating with their doctors and specialists. The print is standard font (12 point), although it uses colored ink, and the pamphlet is six pages in length (front and back).

Cancer and the Elderly, American Cancer Society, 1988. This is another booklet published by the American Cancer Society aimed at educating the public about cancer in the elderly population and its diagnosis, prognosis, and treatment. Information about care of elderly cancer patients is also provided. The entire booklet is 5.5" x 8.5" and printed in black and white text. The print is very small (8- or 9- point font, such as newspaper or magazine) and the booklet is 19 pages in length. Important information is presented in a series of articles (similar to those found in refereed journals) and a bibliography accompanies each article.

Aging, No. 360, Administration on Aging, 1990. Aging is a magazine published quarterly by the U.S. Administration on Aging. The format (in content, shape, and size) is similar to those found on most newsstands (without advertisements). A series of articles addressing topics of interest to the elderly can be found in this journal, and the cover and pages are of magazine, glossy quality. The print is also standard for a magazine, but the majority of the journal is printed in black and white. Several issues are devoted to a specific issue such as legal services for the elderly or diet and nutrition. Participants were asked to critique the legal services and/or the elder abuse editions of the magazine, which are 57 pages and 137 pages in length, respectively.

Age Page, National Institute on Aging. The Age Page is a series of one or two page 8.5" x 11" informational sheets produced for the elderly by the National Institute on Aging. The print is of large font (16 point) and black and white. The Age Page covers a wide range of health topics such as dietary supplements, digestion, and sleep disorders.

Age Pages are also printed as standard fold-out brochures covering a range of topics and issues. The brochures are usually a bit more lively, featuring some graphics, as well as text boxes and titles printed in colored ink. However, the print font is often smaller, only 12 or 14 point.

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Your Medicare Handbook: 1996, Health Care Financing Administration. This 8.5" x 11" guide to the 1996 Medicare program is produced in booklet form and frequently disseminated in mass mailings to retired citizens. The booklet was designed to provide readers with basic information about the Medicare program and to answer frequently asked questions. Topics such as fee-for-service, managed care, skilled nursing facilities, and hospice care are also discussed. Readers also learn how to appeal claims. A glossary of terms and a list of state Medicare agencies is also provided. The print is very large (16 point) and text boxes set off important topics or frequently asked questions.

IV. Findings

This section of the report presents the findings from each of the four types of discussion groups held. While differences between participants' responses based on setting (urban vs. rural) were slight, these are discussed where relevant.

A. Elderly Focus Groups

As previously discussed, participants for the elderly focus groups were recruited from a variety of sources. While the main criteria for participating in the discussion group was age (55 years or older), a special effort was made to balance the focus groups with elderly who live independently, those who live with a family member (such as a child or grandchild), and those who live in an assisted living facility. Because this project is largely aimed at educating the public on *preventing* disease, injury, and the institutionalization of the elderly (i.e., placement in nursing homes or hospitals), elderly who live in skilled nursing facilities or those who are no longer capable of caring for themselves in any capacity were excluded from the groups. Thus, participants in these groups were generally of stable health, requiring only light to moderate assistance in attending to most activities of daily living. Reflecting the current demographics of elderly in the United States, the majority of participants in these groups were widowed women.

1) Health and Safety information

Sources of Information

Participants in both the urban and rural focus groups were asked to begin the group discussion by thinking about a recent health or safety question

"I've had my doctor forever, he has known me from way back when, so I call him."

they have had and from where or whom they sought advice. Private providers, mainly consisting of personal physicians and nurses, were most frequently consulted by participants. The general consensus across the three groups was that their private doctors were most familiar with their personal health and would thus be the most knowledgeable, if not the most logical, source of information.

Beyond their private doctors, few could even think of anyone else to call or consult. However, upon further probing, several participants mentioned calling either their personal pharmacist or a local "all-night" pharmacy with specific questions related to a prescription or certain medications. Several participants mentioned that they had built a rapport with their local pharmacists and because most prescription histories are now maintained on a database at the local pharmacy, they felt increasingly comfortable consulting them. Although rarely mentioned, a few participants had

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consulted health hotlines either publicized in the local telephone book or sponsored by their insurance companies.

A few participants mentioned that they frequently consult family members who are in the health care profession, such as nurses or physicians. Again, the issue of knowledge and trust was paramount. Those participants who did not enjoy such a luxury wished that they did, again citing the advantages of having access to someone who is knowledgeable about them and their health.

Although personal doctors and nurses were cited as the most common source of information, most participants stated that on many occasions they had encountered difficulties receiving timely information. Physicians' busy schedules, complicated telephone answering systems, and rushed office visits were thought by many to be the underlying causes for their unanswered questions.

Health and Safety Concerns

The vast majority of focus group participants had very specific health and safety concerns, most of which were directly related to a current or recent illness or injury. Thus, responses to this question were extremely varied. However, when asked to think of general health concerns as well as safety issues, participants' responses were much more similar. In general, falling and injuring backs and hips was a leading concern. The steep mortality associated with hip fractures was well known to elderly participants, thus contributing to their heightened awareness of potentially dangerous situations such as steep stairs, icy sidewalks, and escalators. In fact, many had consulted a doctor or nurse about preventing falls both at home or while traveling about. Others reported being hyper-vigilant about medications or conditions which might cause dizziness, which could then lead to a fall and possible hip injury. Consequently, several reported discussing signs of dizziness or faintness with their doctors and/or nurses.

Medications and their side effects and the specific use of medicines were also leading concerns of focus group participants. Participants stated that they had been prescribed several medications and were concerned about potential interactions between them. Few

*"I am on several **different** medications, each from a **different** doctor...what happens if I forget to tell one doctor about my other medicines? Do they talk to each other so that they know what I'm on? What **if there** is a bad reaction between all these drugs? "*

Few felt confident that their doctors were aware of all of the potential interactions between drugs, especially if the medications were prescribed by different physicians. Others

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expressed concern about the necessity of some of their medications and the appropriate use of their medications.

The warning signs of various illnesses common to the elderly also arose as a key health concern of participants. Although several different illnesses or conditions were mentioned, knowledge of the signs of heart attacks, Alzheimer's disease, and cancer were of most importance to participants. Several participants felt that if they were more knowledgeable about the signs and symptoms of various diseases, they could be more vigilant about their health and perhaps even prevent an illness from occurring.

The specialization of modern medicine was also thought to be a major problem among focus group participants. Although many could recognize the importance of seeing a specialist for a specific health problem, many also voiced concern about the degree of communication among different providers. As previously discussed, of particular concern was the interaction between the various medications prescribed by different physicians. Others highlighted the need for improving the extent to which medical records and other important health information is shared among various providers — stating that they wanted all of their providers to be as knowledgeable and as “up to date” as possible with their health condition.

A few participants also raised concerns about the necessity of specialists, citing recent newspaper articles or television exposes about unnecessary referrals to specialists as a moneymaking venture for physicians. This topic prompted a flurry of debate among participants, especially among those who belong to managed care health plans, which they felt limited their access to needed specialists. Whether participants felt that specialists were necessary or not, all agreed that more information was needed on the various types of medical specialists, management of their health care with multiple providers, and their necessity.

Other Topics of Interest

As a natural extension of the discussion about health concerns, participants began to discuss topics on which they would like more information. Again, a litany of health topics was raised, many specific (and often personal) in nature. The most frequently mentioned were those cited above: heart attacks, Alzheimer's disease, and cancer. Participants were especially interested in receiving information on the signs and symptoms of these conditions as well as information on prognoses and forms of treatment. In relation to this information, many also expressed a desire to learn more about the different specialists or experts in these conditions, particularly those located in their communities.

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Again, additional information on medications, their potential side effects, drug interactions, and drug allergies was a top priority for participants. Some expressed a desire to receive more information on discerning a drug allergy from a side effect, while others wanted more information on the specific uses of different drugs (“how they work”). Although many participants noted that pharmacists often provide this information with prescriptions, several pointed out the difficulty in reading the small print size or understanding the complex medical terms in these printouts. Others stated the difficulty of keeping track of this information, which is often printed on loose, small sheets of paper or as a package insert. Although few in number, a small number of participants expressed a desire to learn more about the appropriate use of over-the-counter medications, particularly for pain. With the plethora of medications available today, several participants found it confusing to determine, for example, whether acetaminophen, aspirin, or ibuprofen would be most appropriate for muscle pains or a headache. Others had questions about the difference between generic and name-brand, over-the-counter drugs. Consequently, a book describing the uses for and side effects of both commonly prescribed and commonly used medications was desired by all.

Given that falls were cited as a major health concern of participants, information on preventing falls, such as safetyproofing the home, was also a topic of interest. Several participants had heard of the dangers of throw rugs and icy sidewalks but were afraid that many other elderly had not. Thus, a booklet on preventing falls was thought to be extremely important to the elderly.

With the benefits of health, nutrition, and exercise being frequently-extolled in the current media, many focus group participants expressed a desire to learn more about these topics. Information on proper diet and nutrition, particularly for certain health conditions such as diabetes or high blood pressure, was desired by many. Others desired more general nutrition information, such as ways to maintain their current eating habits but reduce fat or sodium intake. A few also stated that they would like information on creative cooking — making their favorite meals healthier.

Although all agreed on the importance of exercise, many were concerned about its safety, again citing their concerns about falling. Some had adopted a daily regimen of

“Everybody says that exercising is good for you, but how much is an older person supposed to do, what kinds of exercise?”

walking but did not know how far or how fast they needed to walk to impact their health. Others expressed some concern about the lack of safe areas to walk, citing increasing crimes against the elderly and the lack of sidewalks as major obstacles. Thus, information on safe exercises for the elderly, especially those that could be

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done at home, and information on the frequency and duration of exercise were considered important information to disseminate to this population.

Although initially mentioned by only one or two participants per discussion, information on Medicare, Medicaid, and supplemental health insurance sparked a flurry of questions and debate among participants. Growing concern about the future of Medicare has caused many to consider purchasing supplemental insurance, yet few know how much, if any, was needed. Some were also concerned about insurance “scams” and therefore wanted more information on distinguishing legitimate health plans from fraudulent ones. Other focus group participants expressed a desire to learn more about the different types of insurance plans such as managed care and fee-for-service. Additional information about Medicare coverage of dental and vision services was desired by most.

Sharing Information with the Elderly

Participants were next asked to consider means of sharing information about the health concerns they had just mentioned with others in their age group. When asked to consider whether or not they

“Unless the class was about my own health problem, something I was interested in, I would not go—I just would not find it interesting enough to sit in a class for.”

(and their friends or neighbors) would attend a class or informational session on a health or safety topic, most stated they would. Upon further probing, participants stated that unless a class were to address a specific health problem they were currently facing, it would not be very relevant and therefore not very interesting. Others cited lack of transportation as another potential deterrent. In general, however, the thought of attending a class, perhaps conjuring up memories of past school days, did not raise much enthusiasm among participants. Only a class on a specific topic of interest, offered after a recent diagnosis such as a heart attack or Alzheimer’s, would prompt most participants (or their friends) to attend.

Although the location or setting of a health and safety class did not have any impact on participants’ desire to attend, participants in each of the discussion groups were adamant about the importance of offering classes within walking distance to the elderly. Some even suggested offering classes in community centers or apartment complexes where many elderly live as a way to improve attendance and further disseminate important health and safety information. When asked to consider offering health classes in a local church, several participants raised some concerns about the effectiveness of reaching all elderly with such a strategy. Several were concerned that those who are not members of the sponsoring church may feel

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uncomfortable attending, while others were concerned about offering classes at a church when some elderly may be of other faiths. Thus, a health and safety class, within walking distance and held in a “neutral” setting, was thought by most to be the most effective approach.

2) Communication with Providers

Given that personal providers are the main source of information for the elderly, questions in this section sought to further explore the extent to which participants and their providers communicate and, in particular, learn more about what is discussed and how.

Frequently Asked Questions

Although many participants turn to their personal doctors for health and safety information, few reported having had any meaningful conversations with them about their health. Most participants reported feeling rushed during their office visits or confused about what information they did receive. Only in cases where a major illness or condition was diagnosed did participants feel they actually talked to their doctors. Many described office visits and conversations similar to the Socratic method where there was little room or time for them to ask questions. Although most participants reported bringing a list of questions to their doctors’ offices, few reported having received answers to all of these questions. Again, lack of time and/or the doctor’s inability to adequately explain his/her answers were often to blame. A few also noted that often they have several questions to ask their doctor but are forced to choose only one or two of the “most important” questions to ask because the office visit is so short.

While few reported having had conversations with their doctors, most could recall an instance where they were able to discuss (even briefly) a topic of interest or concern. The most frequently discussed topics included diet and nutrition, reducing cholesterol intake, preventing falls, and medications. The issue of driving safety was also mentioned by several participants as an increasing topic of discussion with their providers. Those participants with declining vision often were routinely asked about their driving skills and safety while others were only asked as part of an annual or semi-annual exam. In two cases, participants shared that their doctors had asked them not to drive anymore and that they had agreed. Others were only asked to alter their driving regimen, such as to drive only short distances or to avoid driving at night.

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The Doctor's 'Concerns vs. Personal Concerns

In the context of discussing their health concerns with their doctors, participants were asked to compare or contrast their personal concerns with those of their doctors. It was hoped that

"I worry about the same things my doctor does, but not as much. I just try to live each day at a time."

such a discussion would yield some insights into the degree to which the elderly and their providers agree on important health issues and perhaps predict those areas in which implementing prescribed health or safety recommendations might prove difficult.

Driving safety, smoking cessation, and diet/nutrition were stated by the majority of participants as their doctors' chief concerns regarding their health and safety. While participants shared these concerns, few felt them as strongly as their providers did. A number of participants stated that they felt that their doctors "worried too much" about things or that physicians often feel compelled to "find something to worry about" in an effort to keep people from becoming complacent about their health. Thus, participants often stated that they didn't worry about their health until a *major* problem arose.

Health and Safety Materials

Although the majority of focus group participants had received health and safety materials from their doctors (usually in the form of a pamphlet or brochure on topics such as cholesterol, blood pressure, diabetes, or heart attacks), few found the materials helpful. While imparting some information, most participants felt that brochures and pamphlets were either too complex or too basic, often leaving many unanswered questions. In addition, many of the materials covered "the usual" health information such as heart attacks, high blood pressure, and cancer, but few participants had received any information on specific illnesses or conditions unless they had been diagnosed with an illness. As a result, many participants were left wanting information on the prevention and/or early detection (the warning signs) of diseases and illness.

When asked to generate a "wish list" of health and safety materials, again easy-to-read (and understand) pamphlets on nutrition, exercise, medications, and warning signs of common diseases and illnesses were at the top of the list.

Those participants who had received specific information on a certain illness or condition (usually upon diagnosis) often found the materials very helpful.

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Information on smoking cessation and nicotine control devices was thought to be very helpful to several participants while videos depicting an upcoming surgical procedure had eased the anxious minds of several others.

3) The Role of Public Health Agencies

Across the three elderly focus groups, only one participant had ever used the health department as a source of health and safety information. The overwhelming sentiment among participants was that the role of state and local health departments was very specific in nature, to handle disease outbreaks and to provide care to the indigent. While a few knew that the health department administers preventive services such as flu shots in the winter or childhood immunizations in the late summer, even these services were considered restricted to those in the community without a doctor or means to pay for one.

When asked to consider calling the health department for health or safety related information, the concept was difficult to grasp. Participants had a difficult time thinking of an “appropriate” question to pose, again stating that unless they had a question about a communicable disease, they simply would not call their local health department. This conversation quickly led into a discussion about the role and responsibility of public health agencies. Many participants felt that they simply were not sufficiently informed about what health departments do or the services they offer, while others continued to associate such agencies with disease outbreaks, indigent care, and sanitation. Many were surprised to hear about the different areas of interest and responsibility that Federal, state, and local public health agencies had adopted, such as this particular project, violence prevention, and teen pregnancy.

Because participants found it difficult to describe or understand the role of state and local health departments, they were asked to consider ways in which these agencies could be more useful, particularly to the elderly. Although a few participants expressed a desire for the health department to offer health care services to the elderly, supportive services such as assistance with transportation, social/recreational activities for the elderly, or a health “hotline” were more frequently mentioned. Low-cost van or bus transportation to major hospitals or clinics in the community was considered the most valuable service public health agencies could offer. A 24-hour hotline for after-hours or emergency health questions was also considered by many to be a need that could be met by local health departments.

Flu shots, pneumonia shots, and health screenings for the elderly, often in the form of mobile health vans or health fairs, were other services that some participants had heard were offered by local health departments and all thought were important and

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appropriate functions. Yet, when asked if they would (or had) take advantage of these services, few participants responded in the positive. Again, the prevailing thought was that the health department offers (or should offer) such services to indigent elderly or those without transportation or family to drive them to the doctor's office. In fact, many thought that it would be **inappropriate** of them to receive such services since they had a personal physician and a means of accessing necessary health services. Others simply stated that they would feel more comfortable seeing their private physician since they already had built a rapport with this provider and he/she would be most knowledgeable about their medical history.

In addition, perceived long waits, additional hidden costs, and unsanitary conditions were cited as potential barriers to participants, their neighbors, and their friends accessing health services from the local health department.

After learning about the various services local health departments can and do provide to the elderly, all participants agreed that the public should be made aware of this valuable and often free resource for the elderly. Several participants

"No one really knows what the health department does. I don't even know where the health department is in my neighborhood. Maybe if we knew what they did we would call them."

suggested that health departments sponsor a "senior citizen's day" during which services specifically for the elderly are delivered, health information is disseminated, and only the elderly are served. Others recommended that local health departments simply market themselves more effectively, taking out ads in local newspapers or posting flyers about services they offer and how they can help the elderly. Still others recommended that the health department act as more of a broker of health information, helping the elderly chose the right doctor or health plan and recommending books or other sources of valuable information.

4) Prevention and Public Health Services for the Elderly

As previously discussed, only a handful of focus group participants stated that they would take advantage of preventive services if offered to the elderly, stating that they generally receive most of these services from their personal physicians. However, when asked to describe those services they felt were most important or critical to offer, screenings for blood pressure, glaucoma, dental, and hearing were most frequently mentioned. Several participants stated that they would be interested in accessing these services, especially in light of the fact that there is often a 2- to 3-month wait for doctor's appointments, unless in an emergency. Others expressed

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concern that an 'annual physical, during which many of these services are received, might not be frequent enough to detect potential problems (especially in the elderly) and that access to additional screening services might prove beneficial.

All participants were in agreement that convenient locations and free transportation would be the best strategies for ensuring full access to prevention services. Several participants described the difficulties they regularly encounter arranging transportation to scheduled doctor visits and said that preventive services, even if free, would not be worth the hassle unless transportation could be provided.

Other preventive services, such as flu shots, were also considered important services to provide to the elderly community, but, again, few could say that they would take advantage of them if offered by the local health department. Several participants expressed some concern about the safety and efficacy of flu vaccines, while others simply preferred to receive such services from someone they know and are comfortable with — their doctor.

When asked to consider whether or not a health fair or mobile van, which would travel through the community and deliver services, would be an effective strategy, many agreed, but still had reservations. Some mentioned seeing health fairs at the local shopping malls but considered such sites "too public" a venue to administer such "personal services." Others felt that health fairs or mobile vans were great for "other people," those without transportation, family, or means of paying for a private physician. A few participants who had attended health fairs expressed some frustration with the concept of being screened for a certain illness or condition and not receiving immediate assistance or treatment. These participants felt that if a specific condition or illness were detected in a health screen, a treatment or medication should be immediately prescribed, not merely suggested or a referral made.

A number of participants suggested using local pharmacies as a means of sharing information with the elderly and, perhaps, as a site for administering flu shots or

"The pharmacy is a good place to get brochures, information, while you wait on your prescription ... they even have waiting areas."

health screenings. Pharmacists were considered by quite a few participants to be very knowledgeable and easily accessible, especially given their extended evening and weekend hours. Others mentioned the use of local pharmacies as a place to disseminate important health information to the elderly, suggesting that public health agencies capitalize on the time customers spend waiting for prescriptions to be filled.

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5) Materials Review — Suggested Formats and Venues

While all elderly participants found brochures and pamphlets helpful, many felt that the elderly are inundated with this media, stating that radio or television might be a more interesting and effective way of reaching people. Many participants were excited about the idea of watching a 30-minute video on a specific health topic of interest, and being able to check this tape out for free at a local library or video rental store. Those who preferred reading materials felt that the print size, color, and length of the materials were the key determining factors in whether or not they read certain materials. Newsletters and magazine articles were also considered very favorable formats for sharing health information with the elderly. Several stated that they liked the format of the AARP member newsletters.

In order to receive more specific ideas on what health and safety materials *should* or *should not* look like, participants were also asked to critique health and safety materials already developed and printed for the elderly. Participants were asked to comment on the size, shape, feel, texture, and overall format of these materials as well as their content.

Participants' Critiques and Recommendations

Materials that featured large size fonts and were of standard size (8.5" x 11") were considered the most useful and easily understood. In particular, the ***Medicare Handbook*** and ***the Talking to Your Doctor*** booklet were praised and recommended as excellent examples of useful and interesting formats in which to present health and safety information. While many thought the print was too small, a magazine format, such as the ***Ageing*** periodical, was also considered a new and different way of presenting health information. Several commented that a magazine would attract their attention much more than a brochure or pamphlet, but cautioned that the print would need to be larger and the articles interesting and not too lengthy if their attention was to be held.

Although less “flashy” than their counterparts, the Age ***Page*** informational sheets were also praised by several participants as an effective communication strategy. The large font was considered an advantage as was the brevity of the materials, only one or two pages in length. Materials which did not appear lengthy stood a better chance of being picked up and read or even brought home if displayed in a credenza at the doctor’s office or the local pharmacy. The smaller Age ***Page*** brochures were not as popular nor was the ***Talking with Your Doctor*** pamphlet. A number of participants expressed a strong dislike of keeping track of small pamphlets and brochures and found more substantially sized booklets or magazines easier to locate and maintain.

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The Cancer and the Elderly publication was determined the least helpful of all of the materials presented, with participants citing the small print, complex medical terms, and lengthy articles as prohibitive. Several participants understood the importance of printing some materials in black and white so that they can be easily reproduced, but felt that in such cases graphics and large print could be used to offset the “plainness” of black-and-white text.

When asked to provide feedback on the both the content and the outlay or graphics of the materials reviewed, participants praised the magazine format of the Aging journal and the graphics provided by *the Talking with Your Doctor* booklet. Many found the caricatures amusing and the bulleted items in the margins helpful in quickly pointing out the most important information. One participant however, warned against the use of too many graphics or cartoons, stating that they can appear juvenile and distracting and that they should also be used to demonstrate or impart information, not merely decorate.

Although it contains a wealth of information, the *Foundations of Caregiving* manual was considered too lengthy and, in particular, too bulky or heavy for an older person to pick up and refer to. As one participant stated, “I know it has good information in it, but there is so much there I get tired just looking at it, let alone reading it.” Again, participants cautioned against “overloading” readers with information, much of which may not be relevant to all readers. One participant suggested that such manuals be made into notebooks with sheets that could be added or removed so that readers could tailor them to their own needs, without having to wade through mounds of information to find what they are looking for.

Although many participants stated that a resource directory, listing the names, numbers, and addresses of agencies providing information and services to the elderly would be helpful, when asked to critique the *Resource Directory for Older People*, many stated that a *local* resource directory would be more useful. Several participants noted that not all agencies had toll-free numbers and those that did were often busy because “everyone in the country” is trying to call them. Others felt that national resource directories become outdated and obsolete as soon as they are printed because so many people and agencies move, so they personally found such directories frustrating. However, the relative weight and print size of the directory were praised and many liked the ease of reading afforded by the spiral binding of the book. Spiral binding or three ring binders and tabbed pages were considered important features to making any health and safety manual easy to read and its information easy to locate.

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Other Suggestions

In addition to print media, participants again raised the importance of developing television shows or short videos as a way of disseminating important health and safety information to the elderly. Most participants found watching videos a very enjoyable leisure activity and had thus become comfortable with this format. Those who did not watch television or videos as much offered radio talk shows as another possible medium for reaching the elderly, particularly medical talk shows such as Dr. Laura. Elderly participants living in the more isolated and rural area of Floyd County warned against focusing too much attention on developing radio shows, stating that often smaller cities and towns do not pick up as many radio stations as larger cities and therefore not as many residents tune in. However, television, especially cable television, and VCRs were thought to be in enough abundance to make videos or television spots more accessible to elderly in all parts of the country.

B. Elderly Caring for Elderly Focus Groups: Spouses and Companions

In addition to attending to their own personal health needs, many of America's elderly are also faced with caring for an aging, often sickly spouse or companion. The challenges posed by such a dynamic — caring for oneself while caring for another — are made particularly arduous when faced with the reality of growing old. In an effort to further explore this dynamic, elderly who are caring for an elderly spouse or companion were recruited to participate in this focus group discussion. Emphasis was placed on recruiting those elderly whose spouses or companions are currently living with them, in order to learn more about the daily struggles presented by such a situation.

Participants reported (during the screening interview and the discussion group) that they provide a range of assistance to their spouse or companion. The types of assistance they provide include the following:

- transportation
- managing finances
- housekeeping (cooking, cleaning, and other “chores”)
- personal care and hygiene.

All of the participants in these two discussion groups were women.

IV. Findings

1) Health and Safety Information

Health and Safety Concerns

Given that more than half of the focus group participants' spouses or companions have been diagnosed with Alzheimer's, this condition topped participants' lists of

concerns for their loved ones. In particular, many expressed concern about increasing confusion associated with this condition. Participants shared their worries about the safety of their loved ones cooking, driving, bathing, or, in one case, keeping a gun in the house. Participants shared stories of times in which their loved ones had become confused and had endangered themselves or others. In conjunction with this illness, a handful of participants expressed some concern about their spouses' emotional health, stating that they had begun to detect signs of depression and/or anxiety in their loved ones' behavior.

"As a caregiver, you are under constant strain, don't know when something will happen or what."

Falls, often attributed to Alzheimer's-related confusion or declining vision, were also a leading safety concern among focus group participants. Finances, especially finding appropriate and affordable nursing homes or in-home services, were also a major concern. Many participants were aware that they would not be able to care for their spouses/companions indefinitely and some had begun to consider alternatives to caring for them at home. Others had begun to explore the possibility of receiving support services such as home health services or adult day care. All participants were women.

Sources of Information

While their personal doctor was cited by most participants as their main source of health and safety information, local support groups, visiting nurses, and pharmacists were also frequently consulted. However, a few participants did not feel that they could contact their private provider with a question, stating that their providers were difficult to talk to and often not very responsive, or did not respond in a timely manner. Others stated that while doctors were a good source of medical information, support groups, family members, or friends in similar situations provided more of the "real life" information one needs to care for a sick or disabled loved one. These individuals were also a source of great comfort, support, and empathy — supports valued at least as much as health or safety information. In particular, these individuals were important because they had the ability to impart to others knowledge of what was to come, "the next steps" in caring for a loved one

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whose health is 'declining.

Local poison control centers were offered by one participant as another source of information, especially regarding medications. This participant mentioned that she often called the poison control center to learn more about the side effects and potential interactions between various drugs and found the staff quite helpful in answering her questions. She also commented on the fact that such agencies are often available 24 hours a day and thus could be consulted during late night or evening hours, especially-if a drug allergy was suspected.

Frequently Asked Questions

In addition to Alzheimer's, participants frequently asked questions of doctors, nurses, or friends about medications, diet, and nutrition. As the individual responsible for preparing their spouses/companions' meals, participants were very concerned about preparing healthy foods and ensuring appropriate food intake. Several participants shared their concerns about their loved ones eating enough food or the "right" foods, given their age and/or condition.

Information on appropriate use of medications (both prescribed and over-the-counter) was also a topic on which participants frequently sought additional information. Again, faced with the responsibility for ensuring that their spouse/companion received the appropriate medication, participants found themselves frequently consulting others for information such as side effects, drug interactions, and effectiveness. Participants were very interested in finding safe, effective medications for various types of pains.

Those participants dealing with their spouse's/companion's Alzheimer's often sought information about handling their loved one's behavior. Some desired more information on effective communication strategies, while others sought information on handling confusion or forgetfulness.

Many participants also reported that useful, relevant health and safety information was often difficult to locate, and that frequently they had to search for the information they needed.

Other Topics of Interest

Participants were asked to reflect upon the time during which they first began to care for their spouse or companion

"No one likes to think about what they're going to do when they get older or sick . . . but then it happens and few are prepared . . . some basic information on how to prepare for certain illnesses, or even just getting old, would help."

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and to list any information they would have found helpful to have. The majority of participants wished that they were more aware of the warning signs of Alzheimer's, stating that the illness "took them by surprise" and that its effects were well in place before they could even learn about it. Others commented that prior knowledge of the illness and how it progresses might have saved them much frustration and perhaps better prepared them for what lay ahead. Many lamented that if they had some early indication of the illness, they could have organized their lives, such as their homes or finances, so that they could more adequately care for their spouse/companion. Other participants who were caring for loved ones with other ailments shared this sentiment, with some going even further to state that they wished they had known what to expect clinically, as well as financially, emotionally, and mentally as certain diseases progress.

Health and Safety Classes

As an extension of the conversation about topics of interest and frequently asked questions, participants were asked whether or not a class addressing various health and safety issues would be helpful. All participants stated that they would find such a class useful and that they would attend. In fact, several had attended seminars on Alzheimer's and found them to be very informative. While participants in this particular discussion group were much more enthusiastic about attending a health and safety class than their counterparts in the elderly focus groups, they agreed that health and safety classes would have to be relevant for them to attend. A class covering general health and safety issues which did not seem personally relevant would not arouse enough interest in themselves or their friends or neighbors. Others stated the importance of offering classes either in close proximity to the elderly, providing transportation, and again, holding classes in a neutral location, such as a local community center or college.

In addition to classes on health and safety information, several participants pointed out the potential of support groups as a means of sharing information with elderly in similar situations. As previously discussed, support groups offer participants much needed support and empathy that could not be found in a one-time class or seminar, yet valuable information is often shared at these meetings. Thus, if some support group sessions could function as a class or seminar on various health and safety issues, participants felt that additional elderly could be reached.

2) Personal Health and Safety

Although a difficult task for such devoted caregivers, focus group participants were asked to spend some time thinking about their personal health and well-being,

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especially in light of the fact that they are caring for another.

Sources of Information

Not surprisingly, their personal physicians were consulted most frequently with personal health or safety-related questions, with a few participants also referring to family members or friends in the health care profession.

Frequently Asked Questions

Participants had posed a variety of questions to their providers regarding their personal health care covering both specific, often personal, topics and those more general in nature, such as healthy eating and exercise. Similar to participants in the elderly group, these respondents expressed a desire to learn more about healthy exercises for the elderly and ways to eat healthily, yet enjoyably, and monitor their weight and fat intake. General information on what to expect as they themselves grow older was also a major concern of elderly caregivers, especially since the health and well-being of those they care for is very much linked to their own. Thus, several participants were eager to learn more about future conditions or ailments and any possible physical or mental limitations accompanying them.

Health and Safety Materials

Only a few participants had received any materials from their providers addressing their personal health concerns. In general, these materials were in the form of pamphlets and brochures that covered certain medical tests or procedures such as mammograms or provided information on reducing cholesterol levels. Several participants also mentioned that they had received pamphlets from their insurance companies describing preventive health services and their importance in keeping healthy.

While all were appreciative of the materials they had received, many found them difficult to read due to the small print size or difficult to understand due to the use of complex medical terms. Others described materials “loaded” with information that was too lengthy to read or arouse interest. Materials which provided easy-to-read, practical information were found to be the most helpful and interesting.

Other Topics of Interest

As caregivers, participants were asked to consider other information they would find

“If I am going to take good care of him, I have to take good care of myself.”

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useful or helpful to have access to, focusing their attention on what types of information would make caregiving easier for them, if not on them. All participants agreed that as caregivers, they could use more information on caring for themselves, such as preventing injuries to themselves while caring for their loved ones. Several participants shared their concerns about injuring their backs while lifting, carrying, or moving their spouse or companion, while others were concerned about falling or straining a muscle during such strenuous physical activity.

In addition to concerns about their physical health and safety, all participants agreed that caregivers should be equally concerned about their mental and/or emotional well-being.

“When you are taking care of a loved one, it’s physical, mental, and emotional with you, all of the time.”

Citing depression, exhaustion, and frustration as typical emotional responses to caregiving, participants stated that they would like more information on creative ways of handling these feelings. Others thought that information on respite services, adult day care, or senior recreational services would be helpful so that they could take a well-deserved break from their caregiving responsibilities.

3) Communicating with Providers

During this portion of the discussion, focus group participants were asked to discuss their relationship with both their personal doctors and their loved ones’ doctors. Participants were asked to comment on the quality of their relationship with these providers, and in particular, the degree to which their providers were aware of their health and safety concerns and the quality of communication with their providers.

All stated that on at least one occasion, they had had a conversation with their spouse’s or companion’s physician regarding either their specific health condition or a recent issue or area of concern. In general, participants shared their doctors’ concerns, especially regarding safety issues with Alzheimer’s patients such as driving and cooking. In fact, several participants spoke of cases in which they had collaborated with their loved ones’ physician to develop a sensitive way of taking the car keys away from a spouse or companion who could no longer drive safely. Another participant shared her story in which she was concerned about her husband (diagnosed with early stages of Alzheimer’s) owning a gun and how the physician shared her concerns and helped her convince her husband to allow their sons to keep the gun at their home.

Preventing falls and injuries was another frequently discussed topic and an area of

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shared concern between participants and providers. Physicians were equally concerned about either the caregiver or the spouse/companion falling and injuring themselves while lifting or moving about.

Communicating with Personal Providers

As previously discussed, participants' personal providers had expressed great concern about personal injuries such as muscle or back strain and falling while lifting or moving their loved ones. As participants either grow older or their own ailments begin to "flare up," personal doctors grow increasingly concerned about the safety and prudence of their patients caring for others. Other participants stated that their doctors were worried that they were not getting enough rest or "diversion" and that if this continued, it would lead to depression, frustration, or burnout.

Although participants stated that their providers had expressed concern for their well-being as both patients and caregivers, few had received any health or safety information on preserving their own health while caring for others. A few of the participants caring for Alzheimer's patients had received a book entitled "The 36-Hour Day," but none had received it from their personal doctor; rather they had received it through a local support group or their spouses' physician. This book, which provides a realistic look at (and recommendations for) caring for an Alzheimer's patient, was considered a valuable resource for caregivers.

Communicating with Spouses and Companions

Although Alzheimer's had made communication with some participants' spouses or companions extremely difficult, participants nonetheless provided valuable insights into the difficulties they faced conveying their health and safety concerns to their loved ones.

As expected, participants faced the greatest difficulties trying to convince their spouses or companions that certain activities such as cooking and driving were no longer safe. Participants struggled with trying to preserve their spouses'/companions' sense of independence and pride while ensuring their safety. Participants felt that this was an even more difficult concept to convey to men, citing traditional gender roles, especially about driving, as a major barrier. Spouses, especially men, found it difficult to relinquish the perceived independence and freedom offered by an automobile.

Along similar lines, female participants also discussed the difficulties their husbands faced in relinquishing their role as the proverbial "head of the household." As conditions such as Alzheimer's or stroke make independent living more difficult, it

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often becomes necessary for women to adopt the more traditionally male tasks of driving, managing finances, or household maintenance, a concept that is unfamiliar and uncomfortable for men of an older, more “traditional” generation. The sense of weakness or lack of self-worth that accompanies such a reality is often difficult for men to bear.

Participants responsible for caring for female companions also shared their struggles trying to maintain the independence and dignity of their loved ones yet ensure their safety. As one participant pointed out, women are often widowed and thus have the opportunity to spend a portion of their older lives living independently. Thus, when their health declines to the point that another must care for them, similar challenges are faced as with husbands. Again, the decision to quit driving was mentioned as a difficult subject to discuss, as was cooking safety. In addition, several participants spoke of the difficulties they faced trying to convince their loved ones to safetyproof their homes, which often required the rearrangement or removal of items. As one participant explained, “it is difficult to go in someone else’s house and tell them what they need to get rid of or how to arrange their furniture, even if it is in their best interest.” Again, convincing others of the importance of ensuring their personal safety was deemed perhaps the most arduous task of all. Several participants noted that information on tactful and creative ways to communicate such messages with their loved ones would be very helpful.

4) The Role of Public Health Agencies

As with their counterparts in the elderly focus groups, none of the focus group participants had consulted the local health department for information on any health or safety issue. When asked why they had not, participants simply responded that they just had not thought about it. Only one participant personally knew of someone who had called the health department with a question, and unfortunately she did not receive a helpful reply, which served as a deterrent to other friends and neighbors with whom she shared her experiences.

Participants offered a number of reasons why they had not considered the local health department a resource for health and safety information, most stating that their personal doctors were the more appropriate persons to call because they were most familiar with their personal health situation. Others, who had heard tales of automated voice systems and answering services “often used by government agencies,” found these difficult to maneuver and therefore a deterrent. Still others held more traditional views of health departments as a resource for disease outbreaks or indigent care and therefore not appropriate for them.

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Participants were also asked to consider the various ways that the health department could be of more use to them and others like them in the community. Again, assistance with transportation was considered an area where health

departments could be most useful to the elderly. Additionally, participants felt that the health department should adopt a more visible role in disseminating information about the availability of services (both public and private) to the elderly, especially in their communities. Several participants commented on the difficulties they had encountered when trying to get information on support groups, respite care, and insurance plans and many felt that these were areas where assistance from the health department was desperately needed.

“Local health departments could be more helpful in providing information to the elderly to help them plan ahead for things like long-term care, in-home support, etc. Sometimes information itself is the hardest thing to find.”

Others thought that the health department should perhaps offer classes or recreational activities for the elderly at which health and safety information could be shared. A few participants also felt that local health departments should simply make the community more aware of the services they provide, especially those of use to the elderly.

5) Prevention and Public Health Services

Participants in this particular discussion group could list a number of preventive and early detection services they felt would be valuable to offer to the elderly population. Such services included flu shots, blood pressure screenings, eye exams, and dental exams. While a number of participants stated that they would take advantage of such services if offered, many questioned the appropriateness of doing so, considering that they had private physicians who already offer such services, and felt that other elderly would most likely feel the same way.

Lingering stigma about the health department as a resource for the poor was also raised as a potential barrier to services, while others felt that the general lack of information or knowledge about the health department (what it does and who it serves) would also prevent many elderly from accessing their services. Convenient times and transportation assistance were again raised as critical components to ensuring widespread access to preventive services. In general, however, participants agreed that prevention and public health services should be made more readily available to the elderly and that this was an appropriate role for public health agencies.

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6) Materials Review — Suggested Formats and Venues

Respondents in these two discussion groups were asked to review the same set of materials as other focus group participants. Again, they were asked to provide feedback on not only the content of materials but on their format, shape, color, and size.

Not surprisingly, the *Cancer and the Elderly* booklet was found to be the most difficult material to read or understand. Citing the small print, medical journal format, and lack of graphics, participants found this booklet the least helpful. On the other hand, the *Aging* magazine received rave reviews despite its small print. Participants found the magazine format enticing and the articles, many of which discuss “the good old days,” extremely interesting and relevant to the elderly. As one participant stated, “It looks like something you would want to pick up and read.”

The spiral binding of *the Resource Directory for Older People* was again praised, with participants commenting on the ease with which they could turn pages and find information. They also found its smaller, yet substantial, size useful and easy to either tote or file on a bookcase. The glossy cardstock cover of the *Foundations of Caregiving* manual was also praised, with many stating the importance of making health and safety information durable and therefore long lasting, by protecting it from spills. However, the small print, weight, and size of the manual were found to be less desirable, while the content appeared interesting and informative to many.

The *Age Page* one- and two-page informational sheets were more well liked than their counterparts, the brochures, again because of their larger size and brevity. Similarly, the *Talking with Your Doctor* booklet was preferred to the pamphlet, for many of the same reasons. The format of *the Talking with Your Doctor* booklet was also praised, while some felt that the print size should be larger. All agreed that the content was very valuable and an area where more information was needed.

The size, font, content, and color of the *Medicare Handbook* made it another favorite with focus group participants. A number of participants had received copies in the mail from the Federal government and had found it both useful and easy to read. Others who had not seen it prior to the discussion group agreed. The semi-glossy cover was also considered an advantage, again protecting it from spills or other mishaps.

Other Suggestions

Participants were asked to provide some final, yet general, suggestions on useful

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formats for disseminating health and safety information to the elderly. In the area of print media, participants highlighted the importance of large fonts, concise information, and interesting content as critical to developing health and safety information that would at least be read, if not referred to again. Larger size, yet not too heavy, booklets or manuals were recommended because they could be easily picked up and stored by aging hands. Other participants cautioned about keeping information as brief as possible, warning that lengthy booklets, articles, or even brochures would most likely be found tiresome, if not boring. Several participants suggested combining interesting non-health related articles with health and safety information so as to initially attract readers to the materials and then perhaps entice them into reading some of the other more health-related information.

Focus group participants found the idea of a health and safety manual designed especially for elderly caregivers an intriguing idea. Information on diet and nutrition, medication safety, preventing falls, safe exercises, warning signs of diseases and illnesses, managing finances, communication with providers, and information on locating affordable, quality health care were considered the most critical items to include in the manual. In addition, assistance with locating quality in-home support, a suitable nursing home, and information on various types of insurance plans and public assistance were also considered important to include in the manual. When asked to consider a potential format for this information, several participants suggested a spiral-bound or notebook-type manual, with tabbed pages for easy reference, as an ideal format. One participant suggested that the manual take the form of a some cookbooks, with an index as well as tabbed pages and pockets or three-ring binders into which addition information could be added (or removed) as determined by the individual reader. Others once again stressed the importance of large fonts and graphics to “liven” up the document, while another cautioned about printing colored ink on colored paper. As this participant explained, “even though colors make materials more attractive, you have to think about older eyes reading them. It is easier to differentiate black and white than some of those colored inks.”

Videotapes and television shows were also suggested as potential formats for disseminating health and safety information to the elderly. Television spots during daytime soap operas were thought to be a useful mechanisms for reaching older viewers, while others felt that short videotapes would be helpful. Videotapes were also thought to be very helpful because they could clearly demonstrate how certain types of health or safety information should be adopted or implemented. For example, an exercise tape for older people with someone demonstrating how to exercise safely was suggested by one participant, while another thought that a videotape (in a similar format to the PBS show “This Old House”) depicting the narrator walking through a house and finding and correcting potential safety hazards would be extremely useful to many elderly.

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In conclusion, participants highlighted the importance of broad dissemination of health and safety materials to the elderly. Given that many elderly are homebound, much information is not readily available unless it comes through the mail, television or radio, the doctor's office, or, in some cases, the local hospital, which is often then too late. Thus, participants stressed the importance of capitalizing on the places where elderly spend time and live as the most effective method of reaching as many older Americans as possible.

C. Family Members — Caring for an Aging Parent or Grandparent

Like their counterparts in the elderly spouses/companions focus groups, participants in the family members discussion group also face the task of caring for an aging, often infirm loved one. While their situations may not be complicated by their own declining health, younger family members face a number of challenges such as children, marriages, careers, and finances, which often work in partnership to further confound the task of providing for an aging loved one.

With the exception of one woman who cares for her older aunt, participants in these two discussion groups were responsible for caring for a parent, grandparent, or in-law. Because we were interested in learning more about the challenges family members face in providing direct and frequent assistance to aging relatives (e.g., assistance with activities of daily living), family members whose relatives live in skilled nursing facilities (where residents generally receive a high level of assistance with most tasks) were excluded from the study. Efforts were also made to balance the discussion groups with family members whose relatives live with them and those whose relatives live independently or in an assisted (light to moderate) living situation. Participants reported providing a range of assistance to their older relatives, including the following:

- transportation
- managing finances
- housekeeping (cooking, cleaning, and other “chores”)
- personal care and hygiene
- companionship.

All but one of the participants were women.

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1) Health and Safety Information

Main Health Concerns

Family members across both of the discussion groups shared similar concerns about their loved ones' health and safety. Health-related concerns included diet and nutrition, exercise, and depression, while driving and cooking safety were the primary safety-related concerns. Family members also shared their concerns about finding quality, affordable in-home support such as visiting nurses or home health aides. Along similar lines, many participants were concerned about locating quality, affordable nursing homes or perhaps transitional care, in anticipation of a time when they could no longer care for their relatives themselves.

Limitations on relatives' self-sufficiency were also a great concern for family members, with many stating that declining vision and overall general health would make relatives more dependent on them, thus further straining their often busy and overextended lives. As one family member noted, "As they grow older or get sicker, they need even more help and they need it more of the time . . . I am also caring for my husband and kids. How am I going to do this too? . . . I am afraid that something will give."

Poor communication with older relatives was also perceived to pose a major threat to their health and safety. Family members were very concerned about their relatives' reluctance

to ask for help, preferring to attempt to do things on their own (such as climbing ladders, driving at night, or walking long distances) that often place them in physical danger. Fear of being a burden combined with a desire to maintain their independence and self-sufficiency were often to blame for relatives' reluctance to call on family members for help.

"Often parents will wait until there is a crisis, something bad has happened, before they let you know they need help."

Sources of Information

Family members were asked to list their usual sources of information for addressing these issues. Those providers directly involved in caring for their aging relatives (such as visiting nurses, nurses at the local hospital or the doctor's office, nurses at an adult day care or respite program, or physicians) were frequently consulted by family members. In Floyd County, however, several participants mentioned that they frequently called the local community care program for senior citizens, which deploys home health aides to the elderly, with their questions or concerns. As with

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the elderly and elderly spouses groups, providers directly involved with their relatives were deemed the most knowledgeable and relevant sources of information.

Although few in number, some participants also mentioned calling the local hospital, especially its social work department, for information regarding the health and safety of their relatives. In particular, these sources of information were consulted when family members wanted to learn more about available services in the community or if they had questions regarding eligibility for state or Federal programs.

Frequently Asked Questions

While most family members generally consult personal providers (or others) about very specific problems related to their loved ones' personal health care or condition, a few commonly asked questions or topics did arise. Information about finding quality health care (in-home, transitional, or institutional) was a leading topic along with safetyproofing the home.

Across the two groups, family members reported that ,quite frequently, needed health and safety information is either unavailable or extremely difficult to find. Participants were quite disappointed with physicians' lack of knowledge or awareness of services in the community for the elderly. Others were frustrated by the fact that some providers could offer little or no assistance beyond those questions more biomedical in nature.

Other Topics of Interest

Family members were able to generate a rather exhaustive list of topics or types of information that they wished they had access to, both currently and when they first began caring for their older relative. Although very broad in scope, all participants agreed

“It is easy to find or get lists of nursing homes, assisted living facilities, home health agencies, etc . . . Our doctor gave us a list. But we had no background information on them and we did not know what to look for . . . We visited some places and they weren 't very nice. ”

that a guide or handbook to caring for an older relative would be an invaluable resource. Specifically, information on finding quality in-home support, transitional care, or nursing homes was desired by most participants as was information on appropriate medical or safety equipment for the home.

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Assistance in planning for the care of an older relative was also deemed crucial, particularly tips on both financially and emotionally preparing for such an undertaking. Several

participants pointed out the need for practical advice such

as building in extra time when traveling with older relatives or finding creative ways to provide assistance to the elderly while maintaining their pride and sense of self-sufficiency. Others wanted more information on balancing their personal needs with those of their relatives and emotionally adjusting to the fact that their roles with their parents had reversed. As one participant explained, “How do you take charge of caring for your parent when they were always the one who took care of you?”

*“One of the things I’ve learned was how slow older people can move . . . You have to build in extra time when you **are** traveling with them because either they walk slower, need more time getting dressed, or perhaps they have a wheelchair you need to pack and unpack. ”*

When asked to consider what additional types of information they could use, family members also mentioned that they could use more information about insurance plans, what the options are, what is covered,

and how much coverage is needed. Information on support groups for both themselves and their older relatives was also frequently requested by participants. Support groups were considered an excellent source of not only emotional support, but additional information — a place where members could formally receive information and learn from each other. Assistance with financially preparing for the care of their loved ones, what expenses to expect, and how to get financial assistance were additional topics suggested by family members.

*“Support groups are a great source of not **only** support but information. You can see how others are handling things and learn from them. ”*

Sharing Information with Others

In addition to generating a list of desired information, family members were asked to discuss possible ways of sharing this information with the elderly and to specifically consider the advantages and disadvantages of health and safety classes or seminars. Most participants stated that they would attend a health and safety class, especially if the class covered a topic of interest. In fact, classes on safetyproofing the home were considered a very interesting topic by participants in one of the groups, while others listed more specific health topics such as Alzheimer’s, heart disease, and diet and nutrition as other possible areas of interest.

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Other factors such as location, length, and time of day were also considered important predictors of whether family members (and their family, friends, or neighbors) would attend. Classes short in duration (perhaps an hour), offered in their community, and during convenient times (on a weekend or after work) would be more well attended.

Family members were also asked to think about whether or not their older relatives would attend a health and safety class, if offered. Some felt that their older relatives would be reluctant to attend a class, especially alone or if it were held somewhere unfamiliar. Lack of transportation was also considered a significant barrier to the elderly attending a class or seminar. In general, participants felt that if they attended the class with their relatives, they would be more willing to participate.

2) Personal Health and Safety

Family members' concerns about their personal health and safety were almost entirely discussed in relation to the health of the relatives they cared for. Several of the older family members expressed great concern about straining their backs or muscles while trying to lift or support their relatives. Several older family members also had serious health conditions of their own, such as cancer, a heart condition, and a nervous system disorder that was often exacerbated as they sought to care for their loved ones.

A few family members also expressed some concern about the impact of caregiving on their personal lives, such as their relationships with their children or spouses, while others were concerned about their emotional or mental health and issues such as depression or guilt. Watching the slow deterioration of a loved one's health, especially when associated with Alzheimer's, was a particularly grueling ordeal for participants.

"I get so depressed thinking about how my mom was and how she is now."

Participants in the urban focus group setting had received little information on keeping themselves healthy and safe, unless accompanied by a specific diagnosis or detected health condition. Similarly, few of their counterparts in Floyd County had received any information on their personal health or safety. However, two of the participants suffering from serious, personal health problems had received information from their providers, on both the illness itself and information on maintaining their health while caring for another. In both of these cases, participants had extensive conversations with their providers about their personal health status

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and the impact of certain activities such as lifting, bending, or excessive **physical** exertion.

3) Health and Safety Communication

Communicating with Loved Ones

Although all family members had tried to communicate important health and safety information to their relatives, all had encountered some level of difficulty or resistance.

“Every blouse my mother owns has a burnt spot on the sleeve ... this scares me because I know she got it while cooking.”

Health and safety issues they found most difficult to either discuss or explain were cooking safety and driving. Several participants shared stories of kitchen fires, gas stoves left on and unattended, and burnt pots or, in one case, articles of clothing.

Driving safety, specifically when and how to prohibit older relatives from driving, was also a “touchy” topic of discussion between family members and their relatives. Some

“I had been trying to coax my mother into selling her car, to give up driving. But it wasn't until our neighbors and others from our area started to call us and ask us to keep her off the roads . . . When that happened, I knew I had to do something, fast. ”

participants told stories of parents who had accused them of “meddling” when they

suggested that driving was no longer safe, while others had met outright opposition to the idea. Ironically, **children** were faced with the task of trying to monitor or prevent their **parents** from driving, with some being forced to take away driving privileges all together.

Convincing relatives when and how to ask for help was also a difficult task facing many caregivers. Relatives who had been independent and active their entire lives had difficulty accepting the fact that they needed to “slow down,” while others resented being told what to do and when by their children. Family members also struggled to find ways of balancing their relatives' need for independence with their concerns for their safety and well-being. Although participants swapped stories and examples of creative ways in which they had convinced a relative to stop driving, learn to use a microwave, or ask for help, few expressed faith that these ideas would work in their particular situation. After exhausting numerous possibilities and not knowing where else to turn for help, one daughter concluded, “At some point you

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just have to cross your fingers and hope they will be okay on their own . . . Just like they did with us.”

Communicating with Providers

The majority of family members reported that they had some type of conversation with providers (usually their relative’s) about their concerns for their loved ones’ health

“Sometimes the elderly have 8, 10, or 12 prescriptions. Are all of these drugs really necessary?”

and/or safety. Again, driving safety was a frequently discussed topic, as was the safety and effectiveness of medications. Specifically, several participants had growing concerns about the necessity of the various drugs prescribed to their relatives, as well as possible adverse reactions to drugs or interactions between them. The appropriate use of over-the-counter medications, especially for pain, had also been discussed with providers. Family members felt that pain levels were very different and therefore might require a specific type of pain killer, depending on the location or severity of the pain. Thus, several had sought the advice of providers in answering this question,

A few family members had expressed some concern about the level of communication or coordination of care among the various doctors and specialists attending to their relatives’ care. Some participants had experienced some differences of opinion among providers or conflicts in recommendations or treatments and were thus left confused about which advice to heed.

As previously discussed, two participants have had the opportunity to have very specific conversations with providers about maintaining their personal health while caring for their mothers. In these cases, both family members had discussed with their providers the safety of performing specific tasks such

“When my mother became sick, I talked to my doctor, who is also my mom’s doctor, about caring for her since I also care for my husband who has Alzheimer’s . . . He said that I should not try to keep her at home with me because I would be overburdened and this wouldn’t be good for my health . . . I am glad that I talked to him . . . his concerns validated mine, made me feel less guilty. ”

as lifting, bending, or moving things (or people) and the potential impact of such physical activity on their own health. In both cases, participants were advised to limit physical activity or were given some safe parameters within which to operate.

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When asked to comment on the usefulness of advice or information received from providers, responses were mixed. Some participants were very pleased with the information and feedback they had received, while others found providers either too busy to answer their questions or simply ill-informed.

4) The Role of Public Health Agencies

Across the two focus groups for family members, none of the participants had ever called the health department for information or answers to a health or safety-related question. As with participants in the focus groups for the elderly and spouses/companions, no one had even really considered the health department as a resource. Similarly, respondents in these focus groups did not view the health department as an appropriate source of health and safety information, especially for the elderly, and many still associated public health agencies with disease outbreaks. Others felt they really did not know what the scope of responsibility or the role of local health departments was and many were surprised to hear how diverse the public health mission had become. Many were also unaware of the relationship between CDC and state and local health departments and no one could think of a family member, friend, or neighbor who had called the health department with a health or safety question.

Disseminating important health and safety information to the community and providing preventive services were considered key services that could or should be offered by local health departments. In general, however, family members felt that health departments should focus their attention and efforts on increasing their visibility and general awareness of their services.

5) Prevention and Public Health Services for the Elderly

As discussed above, a number of family members felt that preventive services such as dental exams or flu shots were important services to offer to the elderly, yet several questioned whether or not they would be used because many elderly would prefer to see their private providers. Thus, participants in both groups turned their attention to developing a list of those services that are not readily available or easily accessible by most elderly and their families.

Safe exercises, healthy eating, medications (use, side effects, interactions), driving safety, and safety at home (preventing falls, cooking safety) were areas where many felt local or state public health agencies could take the lead in educating the public, especially the elderly. Others recommended that health departments develop local

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or state resource guides, which could provide information such as the location and times of health and recreational services in the community or lists of area specialists, all of which were thought to be desperately needed.

One family member suggested that health departments develop “survival kits” for both the elderly and caregivers. These survival kits would contain not only useful and relevant information regarding health and safety, but also would include resource directories and first aid information. Items useful to the elderly (and those who care for them) such as pill containers, lists of important phone numbers, or reminder calendars about doctors’ appointments could also be included as a part of these survival kits, along with coupons for drug store items and medical equipment.

One participant suggested that local health departments offer a course on caregiving, with a prevention focus, targeting those families whose loved ones are still living independently or are in the initial stages of requiring care and assistance. Several participants agreed, stating that much of the information they have received as caregivers, they received too late, “after the fact.” A short course or seminar on how to plan and what to expect would prove very beneficial and perhaps prevent unnecessary stress and strain brought about by a sudden illness or injury.

“Often times you learn about a health class too late, once your parent is in the hospital or a nursing home . . . then you get all kinds of information. ”

Not surprisingly, transportation (especially for those living in more outlying areas where public transportation is scant and taxis even more inaccessible) was considered critical to ensuring that the elderly take advantage of preventive and public health services. Mobile vans and health fairs that travel to local churches, apartment complexes, or senior centers were considered to be an excellent way to reach the elderly, particularly those without families to transport them or financial access to health care services via a private provider. Family members also stressed the importance of offering such services at times convenient to caregivers, such as after work or on weekends’, so that they could drive their relatives to these services. If these considerations were met, family members felt that many elderly and their families would take advantage of these services.

6) **Materials Review — Suggested Formats and Venues**

Although participants in the elderly and elderly spouses/companions focus groups found both of ***the Aging*** magazines a useful format for disseminating information to

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the elderly, several family members found the graphic depictions of the elderly depressing. According to these participants, many of the pictures they see, both in the *Aging* magazine and in the general media, depict the elderly as “hunched over,” extremely old, decrepit, if not dying. In addition, depressing topics such as illness, death, abuse, or dementia were “overdone” topics of discussion. Thus, family members stressed the importance of using pictures and graphics depicting lively, happy older adults, with more upbeat messages to reach older people and perhaps combat the depressing images that are so pervasive in our society.

Large size and print items such as *the Age Page* sheets, *the Medicare Handbook*, and *the Talking with Your Doctor* booklet were all well received by family members, as was the *Foundations of Caregiving* manual. However, several family members suggested ways in which such manuals could be made more “user friendly” by adding a spiral binding (such as that of the *Resource Directory for Older People*) tabs so that information can be easily located, and a glossary of terms. The *Cancer and the Elderly* booklet again was found to be too difficult to read and understand.

Several family members suggested other materials already in print such as *The 36 Hour Day* or *the Caregiving for Aging Parents* as useful resources for caregivers. Others wished for materials that provide advice on managing relatives’ health care, finding quality and affordable support services, and planning for the future.

Other Suggestions

Videos and local cable television shows were frequently suggested formats for disseminating information to both the elderly and those caring for them. Visual examples or depictions of people performing caregiving tasks were thought by some to be useful ideas for educating caregivers, while others suggested the use of an active older person to “model” certain healthy behaviors for the elderly. Radio talk shows, however, were more popular among families living in urban settings than those in the more remote areas surrounding Floyd county. Again, participants stressed the importance of widespread dissemination of health and safety information and services, to ensure that as many elderly as possible and their families had access to these needed services.

D. **Elder Care Providers**

Participants in this final discussion group consisted of persons directly involved in the delivery of services to the elderly. Again, because the focus of the project is on reaching the elderly population before they are injured or hospitalized, special efforts were made to recruit individuals who serve clients who require moderate or little assistance. In addition, trends

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in services for the elderly indicate a rise in the use of paraprofessionals (non-medically trained personnel) and support services such as home health, respite, and adult day care. We wanted to hear from providers working directly in this rapidly growing field.

Special efforts were taken to achieve a balance between providers who work in the homes of the elderly, those who work in assisted living facilities, and those who work in day care or respite centers. In addition, providers with years of experience serving the elderly and those with some level of (non-medical) training were balanced against those who were new to the field and/or had little training or field experience.

Providers who participated in these groups offered the following range of services to the elderly:

- personal care services (such as assistance with personal hygiene)
- light housekeeping
- recreational support and/or therapy
- in-home health assessments
- respite care
- private duty sitting.

All participants in these discussion groups were women.

1) Health and Safety information

Sources of Information

Supervisors, clinical or nursing directors, and other colleagues (e.g. social workers) were described by providers as their usual sources of information regarding the care and safety of their clients. These individuals

“Often it’s your supervisor or the case manager who assigns you clients, so they have the most information on their medical history, situations to be aware of, things like that.”

were described as the most easily accessible sources of information as well as the most knowledgeable and appropriate, given that many had professional degrees in health care (such as a nursing or clinical social work degree). In addition, several providers indicated that they found these persons to be the most relevant source of information, since they often were very familiar with the assigned client and their health history and medical conditions. Alternatively, providers who were self-employed and therefore had no direct line of authority to report to or consult relied heavily on medical reference books and the advice of colleagues or friends,

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especially those in the health care profession, such as nurses or social workers.

Frequently Asked Questions

Providers' most frequently asked questions often revolved around handling their clients' behavior, including changes in their behavior. How to respond to combative behavior, mood swings, and non-compliance were providers' chief concerns. Non-compliance with medications and prescribed diets or medical equipment were of particular concern for some providers, who feared that such behavior would lead to further injury or hospitalization. Thus, they found themselves frequently consulting others, including family members, for creative ways to promote healthy behaviors in their clients.

Other providers expressed concern (and frustration) with clients who displayed combative behavior or mood swings. In an effort to temper their own frustrations, yet maintain respect for their clients, many providers had consulted others on how to sustain this difficult balancing act. Sudden and unexpected changes in behavior were also considered worrisome by providers, leading some to either question their client's mental status or consider the side effects of clients' medications as a possible cause of behavior change. Such situations had led several providers to consult others for assistance in either determining the cause of such changes in behavior and either correcting it, or seeking emergency medical attention. All providers felt that additional information on this topic was critical to their jobs.

When to pursue emergency medical attention was another area where providers found themselves frequently seeking the advice of others. When and how to move (or not move) a client who has fallen was one

"I would like to know more about when to take a client to the emergency room ... Sometimes you go to do a home visit and the client does not look well or doesn't seem well."

area of interest, while other providers expressed a desire to learn more about detecting emergency situations — those times in which medical attention should be sought immediately. Similarly, providers wanted more information about the severity of certain symptoms or conditions, especially those that merit a visit to the emergency room. Again, all providers found immediate access to such information crucial.

Providers also mentioned that they frequently consulted others about keeping elderly clients safe. Information on preventing falls, safetyproofing clients' homes, and the prevention of sleepwalking or "wandering" were on the top of providers' lists of safety concerns and areas in which many desired additional information.

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Several providers reported that more “public health”-related issues, such as preventing the spread of disease, were becoming a growing concern among elder care providers and therefore a more frequent topic of conversation and consultation. In particular, information on communicable diseases such as measles, tuberculosis, and the flu was often sought by providers, as was information on safely handling bodily fluids such as blood.

Finding Readily Accessible Health and Safety Information

None of the providers reported difficulties finding important or required health information. Those who were affiliated with an agency or elder care service enjoyed particularly good access to information. In these situations, supervisors, clinical staff, and colleagues were readily available to answer questions and respond to inquiries quickly. Those who were self-employed and providing freelance services also reported little difficulty finding desired health or safety information. While they did not have direct access to an agency, they had established contacts with other providers, including their clients, whom they frequently contacted if and when questions arose.

Most Useful Sources of Information

As previously discussed, providers found their supervisors and colleagues the most helpful in answering their health or safety related questions. Their clinical training, combined with the relevancy of the information they provide, was considered by many providers to be extremely useful. In addition, several providers in the Floyd County area found the local health department a useful source of information, particularly their community program for the elderly. The Floyd County Hotline, a service which provides a range of health and social services information to Floyd County residents, was also considered very helpful. Other providers in this county found the local hospital, especially its social work department, very supportive.

Other Topics of Interest

As previously discussed, a number of providers expressed an interest in learning more about appropriate ways to respond to combative, unusual, or destructive behavior in their clients. Information on appropriate ways to restrain physically violent clients, as well as ways to prevent clients from wandering out of their rooms or houses and into harm’s way, was desired. A number of providers also indicated that they would like additional information on medications, such as their side effects, potential allergic reactions, and possible drug interactions.

In an effort to generate more suggestions about other types of information that would

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be useful to elder care providers, participants were asked to consider if there was anything they now do differently as a result of health or safety information they have received. With near unanimity, providers responded that they had learned to be patient and supportive with their clients and to treat each of them as an individual. The more experience providers had gained about the impact of certain diseases and illnesses, combined with what they had learned about the aging process — society's response to it and its effects on people's minds and bodies — the more patient and understanding they had become towards their clients. Many had begun to recognize the sense of isolation that often accompanies growing old and found themselves trying to add enjoyment and pleasure to the lives of their clients.

A few providers also discussed the importance of recognizing their boundaries as providers to the elderly, stating the importance of deferring to trained health care professionals to answer more complicated health-related questions that demand an accurate diagnosis. While providers felt that they were becoming more skilled at determining which questions they could answer and which they should refer, several thought that guidelines or parameters of provider behavior would be helpful, especially for those just starting out.

2) Health and Safety Training

While the majority of providers had received some type of training to provide services to the elderly, when further probed on this subject, it was noted that fewer than half of the participants had attended a class, seminar, or course on caring for the elderly. Other providers who had received training had most likely participated in some type of "on-the-job training" during which they had either been paired with a more experienced provider and "shown the ropes" or, in some cases, had attended an orientation. All but one of the self-employed providers had not received any type of training.

Training — Sponsors and Topics

As mentioned above, most providers had received training through their jobs. In some cases, this training was in the form of a new employee orientation followed by a job "shadowing" experience, while others attended regularly scheduled seminars, lectures, and in-services (employer-sponsored training). Several participants mentioned that they had received specific training from sources outside their jobs, often prior to their current employment situation. Several providers had attended classes at local technical or vocational schools, while others had attended classes sponsored by public or private agencies such as the American Red Cross, a local social services agency, or a hospital.

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The topics of training courses attended by providers varied little. First aid, CPR, and infection control were the most common topics covered in addition to lifting, transferring, and moving clients safely. Other popular topics included signs and symptoms of heart attacks, fire prevention, and prescription drug abuse. Only a small number of participants reported ever receiving training in handling combative or otherwise “difficult” clients or working with clients with mental health problems such as clients suffering from depression, hallucinations, or dementia.

Only one participant reported receiving training on stress management and burnout for elder care providers.

Providers found their training in first aid, CPR, and lifting patients, as well as information on infection control, the most useful and relevant in their everyday work. General information some providers had received on the aging process and associated health problems was also found to be very useful and relevant.

Other Topics of Interest

Providers generated a rather lengthy list of critical items they thought were missing from their training, yet should have been covered. Topping this list was additional training on how to work with clients, not merely providing services to the elderly, but how to interact with them. In addition to their desire to learn more about ways to handle difficult behavior, many providers felt ill-prepared for working with aging clients. Many struggled with concepts such as working with clients when they are angry, appropriate handling (and preserving) of clients’ pride, providing assistance to the elderly without enabling them, and maintaining their sense of independence and self-sufficiency. Other providers reported initial difficulties with these concepts, which often led to frustration, anger, and burnout.

Several participants also mentioned that additional training on safetyproofing clients’ rooms or homes would also be useful.

Sexuality among the elderly was another topic mentioned by one or two participants as a critical “missing piece” of their education and training as elder care providers. Several struggled to find ways to curtail their clients’ inappropriate displays of affection, and, in some cases, their infidelities. While they wanted to maintain their professional relationship with their clients and stay out of their personal lives, many felt compelled to intervene when clients displayed behavior that was inappropriate or perhaps harmful.

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practice or **rewound** to provide opportunities for review and more accurate notetaking.

Participants advised that videotapes should be short (no longer than 60 minutes) and depict real-life experiences or scenarios encountered by providers in the field. Several participants shared their frustrations at viewing videos that addressed either outdated or irrelevant topics rarely encountered in the field. When asked to provide examples of the types of “real-life” scenarios they would like to see on videotape, participants responded that scenes depicting a provider handling a combative or angry client, lifting a client, or performing some difficult task such as putting support hose on a client who has difficulty “sitting still” would be more realistic situations.

While providers felt that videotapes should be as “real life” as possible, many also felt that training that clearly demonstrates important concepts and activities that would be encountered, if not performed, by all providers would be the most useful, and the most interesting.

Another participant suggested such experiential training exercises as ear plugs, blurred glasses, confinement to a wheelchair, or the use of a walker as excellent ways of teaching providers what it is like to have certain health conditions such as cataracts or a hearing problem.

3) Communicating with the Elderly

This portion of the discussion focused on exploring the various dynamics of communication between providers and their clients. In particular, participants were asked to focus their thoughts and discussion on the topics of conversations they have had with their clients as well as the nature of these conversations.

Clients’ Concerns/Family Members’ Concerns

Providers reported that many of their clients (and their clients’ families) had shared with them their concerns about falls. Providers stated that many of their clients were familiar with the high mortality associated with hip injuries and thus were very interested in preventing falls and responding appropriately when falls or injuries occurred. Similarly, family members had expressed their concern to providers about safety in the home, citing small apartments (such as those found in senior or assisted living facilities), often cramped with furniture and other belongings, as potential safety hazards.

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While few elderly clients had expressed concern about the safety of their driving, providers reported that family members had frequently stated their concerns about their loved ones continuing to drive. In some cases, providers had been asked to help families come up with a strategy for convincing their relatives to give up driving.

Focus group participants reported that both clients and family members alike had expressed a desire to learn more about finding quality, affordable health care (such as nursing homes, visiting nurses, and in-home support), often in anticipation or preparation for the time when the elderly could no longer live independently or be cared for at home. Information on paying for nursing homes as well as guidance on what to look for in a quality, well managed facility were considered important information to have. In addition, providers also discussed family members' concerns and questions about when to place a loved one in a nursing home.

Convincing the elderly when to call or ask for help was another topic frequently discussed by providers and family members. As the elderly grow older or sicker, family members often become increasingly concerned about their safety, fearing that their elderly relatives will not recognize their limitations and ask for assistance or help when needed. Family members were thus afraid that their older relatives would injure themselves (or perhaps others) in their attempts to care for themselves. Providers reported that they were often consulted on this topic as family members sought new or creative ways to convince their loved ones to ask for their help and assistance.

Information on supplemental health care, specifically when and how much is needed, was also mentioned by a few providers as a key concern of both their clients and their clients' families. Information on Medicare, Medicaid, and disability insurance was cited as a chief concern of clients and their family members.

Providers' Concerns

While most focus group participants shared clients' and family members' health and safety concerns, many had additional worries. Quick, creative, and inexpensive solutions to safetyproofing the home (geared towards family members) were desperately

"Often families go out and spend lots of money on locks, contraptions, or other gadgets aimed at preventing things like falls or wandering. Yet often, it's simple, cheap solutions such as a ribbon across a door frame or bright colored tape on the edge of steps that can keep elderly safe without breaking the bank."

needed. A manual describing easy-to-implement strategies to prevent wandering, falls down stairs, or other unsafe and/or troublesome behaviors was suggested as a

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way to address family members' concerns in this area.

Along similar lines, several providers also suggested the need for a manual or guidebook for family members that explains safe, humane ways to keep the elderly from hurting themselves and others. One provider stated that she is constantly asked by family members if it is okay to lock certain doors at night to prevent loved ones from wandering outside and into danger. Other family members had requested information on handling combative behavior in their older relatives. Thus, a manual which describes safe ways of addressing such tricky situations would be of great use to family members.

Difficult Issues

Providers described a number of issues or concepts they found difficult to either explain to their clients or convince them of their importance. Not surprisingly, driving safety was at the top of providers' lists, in addition to healthy (and safe) eating and the need to safetyproof clients' homes. Given that they are in the position to serve their clients, providers often found it difficult to transcend this professional relationship and advise their clients on how to organize their homes, shop, or store their food. In many cases, providers raised their concerns with family members with the hopes of receiving some support or reinforcement.

Several providers mentioned the challenges posed by mental health problems such as memory loss or depression in conveying important health and safety information. In cases in which their clients were suffering from memory loss, providers found that their clients often forgot either important information or to perform important tasks (such as bathing), while other clients simply became confused. On the other hand, providers serving clients with depression were faced with the task of trying to convince their clients to eat healthily, take their medications, or exercise when many felt that death was not only inevitable but imminent.

Additional Information

Given the difficulties many providers experienced trying to convey certain health and safety information to their clients, focus group participants were asked to consider what types of materials are or would be helpful to share with clients or family members. Again, information on nursing homes, in-home support, and other health services for the elderly was mentioned by several providers, as was information on understanding and communicating with the elderly.

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Food safety 'was a topic participants in one group felt would be very helpful to share with clients. Several participants felt that materials on the proper preparation of specific foods such as chicken or pork as well as information on storing foods might prevent viral infections and food poisoning among the elderly.

"Many elderly are on a fixed budget and try to save money by keeping food as long as possible, even when it starts to go bad . . . They don't want to throw anything away. "

Although Georgia offers relatively mild climates, residents are sometimes faced with extreme weather conditions ranging from sweltering summers to freezing temperatures and icy conditions in the winter. As a result, several providers felt that materials on both hot and cold weather precautions would be useful to share with elderly clients. Signs and symptoms of heat stroke and frostbite in the elderly, as well as information on preventing such conditions, were considered useful pieces of information.

Brief pamphlets or brochures on specific illnesses common to the elderly such as arthritis, diabetes, cholesterol, or high blood pressure, along with information on the specific signs, symptoms, and treatments for these conditions, were also thought to be useful to share with both clients and their families.

4) The Role of Public Health Agencies

Only a few providers reported having contacted their local health department for information, with respondents in the rural group being very happy with the response they received. In particular, the community care program and Elderly Protective Services were praised for their usefulness and support. Providers in the urban group, however, were not as satisfied with the response of their local health departments. An inability to provide consistent, timely, expedient information was considered a weakness of local health departments by participants, citing their business hours (9 to 5 p.m.), automated answering services, and overall bureaucracy as major obstacles. One participant in this group, however, reported having had a positive experience with the local health department, citing the assistance they had provided to her when a resident was found to have active tuberculosis. The health department offered free screenings to all residents, family members, and staff and helped her allay the fears of concerned residents and family members.

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Other participants shared a common sentiment that the health department is simply not the most appropriate resource for providers, considering such problems as disease outbreaks or sanitation as more relevant to

“The health department can only help you with things that they do, their area of expertise, such as baby shots, TB, disease outbreaks ... You can call them with these questions. ”

the work of public health agencies. Interestingly, few participants felt as if they were unaware of the services provided by the health department. Instead, they felt quite informed about the responsibility of public health agencies and had simply determined that the majority of their services were not relevant to the work of elder care providers. Thus, participants were rather surprised to learn about the various areas of interest and expertise of local health departments.

A number of providers also expressed some reluctance to contact the health department, largely out of fear of its regulatory responsibility and licensing requirements.

*“The health department is the **last place** we would call; it makes us and our staff nervous; we view them as regulators, bureaucrats . . . They are the ones who want to give us a hard time, shut us down **if** everything is not quite right. ”*

Providers affiliated with an elder care agency were particularly leery of health departments, fearing audits and surprise inspections. Several participant commented, however, that if they knew exactly which department or person to call (perhaps to avoid the regulatory department) they might consider using the local health department as a resource.

Once providers began to think about the health department as a possible resource to them and/or their clients, they suggested several ways in which the agency could be of more use. Hotlines, open 24 hours, with a “live voice” on the other end were thought to be a good use of public health resources, as were newsletters or updates distributed to agencies serving the elderly, to keep providers informed about upcoming events or health problems on the rise. The provision of services such as flu shots, TB tests, and dental or vision screenings was also thought to be useful, especially if these services were provided free of charge and in locations where the elderly live or frequent.

5) Prevention and Public Health Services

Only a small number of providers felt that dental, vision, or hearing, screening were

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important services to provide to the elderly. Several providers felt that health fairs and mobile vans had been “overdone” and that most elderly would prefer to see their private physicians. Flu shots, however, were still considered an important preventive service to provide, even if the elderly did not take advantage of it as they should.

Several providers felt that public resources would be better spent educating the elderly and the general community through health classes addressing topics such as nutrition and exercise for the elderly.

Health information fairs, which travel through communities, especially to places where the elderly socialize or live, were considered by most providers the most effective method of reaching the elderly population. A health fair that could travel to the elderly (especially the poor) attracted the most attention and support among providers because it would help overcome transportation barriers. Providers also mentioned that they would be willing to either personally drive or arrange for the transport of their clients to receive such services.

6) Materials Review — Suggested Formats and Venues

Participants were asked to review assigned materials while considering their usefulness as manuals or guides for providers, especially in the field. Given that it is specifically designed for caregivers, *Foundations of Caregiving* was highly praised by the majority of providers. They found the content comprehensive, the information relevant and “real,” and the explanations and demonstrations clear. However, several commented that the size and format of the manual did not easily lend itself to use in the field but was more appropriate as either an accompaniment to a training course (which in reality it is) or as a desk reference. Participants felt that spiral binding or a three-ring notebook, with tabbed sections, would make the manual more useful in the field. The glossy cover was praised for its durability, especially against wetness and spills.

Several providers liked the size of *the Resource Directory for Older People*, stating that it could be easily carried in a bag while its spiral binding made turning pages and overall handling much easier.

Several providers also highlighted the importance of using clear and concise language and providing easily understood definitions for medical or complex terms. A glossary of terms was thought to be an excellent way to teach providers, especially those new to the field, complex health and medical terms. A quick reference chart listing commonly prescribed or used medications, their side effects, allergic reactions, and drug interactions was also considered important information to include

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in materials for providers.

Above all else, providers felt that quick and easy access to important information should be considered the most critical element to address when designing materials for providers. As previously discussed, the majority of providers' questions require immediate responses, thus manuals and reference guides should be developed with this reality in mind. Quick reference charts and tables for frequently used information were frequently suggested by some participants, while others recommended placing important information in conspicuous locations, such as the clipboards providers often carry with them on home visits.

V. Summary

This focus group study yielded a wealth of information regarding the need for timely, relevant, and easy-to-understand health and safety information. Although participants' responses were numerous and often varied, there were several key themes or motifs within each population studied. In the sections that follow, these most common or frequently stated topics are summarized by group.

A. Elderly

1) Sources of Information

- **The main sources of health and safety information for elderly focus group participants were their private physicians.** Participants noted, however, that their physicians did not always have time to answer all their questions. Those who had to consult **specialists** worried that their care was not necessarily coordinated by any particular physician. In some cases, participants thought their physicians were overly concerned about health and safety issues.
- **Pharmacists and pharmacies** constituted another important source of information — both the pharmacists as individuals, and the materials available in the pharmacy setting. Although participants praised the useful information available in pharmacy printouts that accompanied their medications, they complained about the small print size and medical jargon in these materials. **Family members** — especially those trained in the medical field — were another often-cited source of information.
- For the elderly patient, the most important features of any interaction with providers were the providers' **knowledge** of the elderly patient's overall condition and the elderly patient's **trust** that the provider would thus manage his or her condition effectively.

2) Main Health and Safety Concerns

Health and safety concerns included:

- falls
- medications and their side effects
- warning signs of Alzheimer's disease, heart attacks, and cancer
- safety-proofing the home
- diet and nutrition, especially regarding diabetes and high blood pressure
- healthier cooking techniques
- safe exercise
- insurance issues — especially how to avoid “scams.”

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3) Dissemination of Information to the Elderly: Formats and Venues

- **Transportation barriers and unfamiliar surroundings would keep most of the elderly away from health and safety classes.** Mobile vans and health fairs are considered too public a setting for asking personal questions about health. With one exception, the elderly participants in these focus groups were not aware of the health department's functions, nor did they view such agencies as potential sources of useful information.
- **Videos and large-font printed materials**, large enough to handle with arthritic hands, were recommended as suitable mechanisms for transmitting health and safety information.

B. Elderly Caring for Elderly: Spouses and Companions

1) Sources of Information

- Spouses/companions **turn to their family members' physicians and nurses and other family members.** **Support groups** were especially valued sources of information (as well as support) among those caring for a spouse or companion with Alzheimer's disease.

2) Main Health and Safety Concerns

- Half of the participants were caring for someone with **Alzheimer's disease.** The confusion and decline associated with that disease were paramount concerns for spouses, as were the disease's consequences in terms of safety, independence, and communication.
- Information on the warning signs of Alzheimer's would have been helpful, to give families time to prepare emotionally and financially.
- **Falls, medications, and financing care in the future** were other concerns.
- **Spouses/companions were also concerned about their own health**, particularly nutrition, exercise, preventing injuries (especially from lifting or moving their spouse or companion), and maintaining their own mental/emotional health.

V. Summary

3) Dissemination of Information to Spouses/Companions: Formats and Venues

- Spouses and companions were more receptive than others to the idea of attending classes or seminars on health and safety topics.
- A video and/or manual specifically designed for this population would be well received. Suggestions included a video following a “This Old House” format, showing how to make each room in the house or apartment safer for an elderly person.
- Spouses/companions were unfamiliar with health departments and their resources.

C. Family Members (children, grandchildren, nieces, nephews, etc.)

1) Sources of Information

- Family members turned to **private physicians** caring for the elderly family member, as well as to the **local hospital’s social work department** (for referrals to other services).

2) Main Health and Safety Concerns

- Concerns include the elderly family member’s **diet, nutrition, and safety (particularly when cooking and driving)**.
- Family members would like more information on:
- **lifting or moving** the elderly family member
- **communicating effectively** with an elderly family member when family roles are reversed
- **convincing elderly family members to ask for help**
- discussing **driving** with family members who are at risk of endangering themselves or others
- the medical management of **severe pain**

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- **medication** interactions and side effects.

3) Dissemination of Information to Family Members: Formats and Venues

- Family members suggested **videos and local cable television** as suitable channels of information.
- Some recommended a “**survival kit**,” perhaps prepared by the health department, with a variety of useful referral telephone numbers, checklists, and tips for caring for an elderly relative.
- **Health departments were not mentioned** as a potential resource or source of information.
- Family members noted that in publications for or about the elderly, **the elderly should be portrayed in a positive light** — as active, alert people, rather than as infirm and feeble.

D. Providers

1) Sources of Information

- Providers who work for an agency turn to their immediate supervisors and/or colleagues; providers who are self-employed turn to colleagues (especially those with a medical background) and/or reference books.

2) Main Health and Safety Concerns

Providers’ concerns include:

- **dealing with the behavior** of elderly clients, especially combative/belligerent behavior and mood swings
 - when (and when not) to seek **emergency care**
 - **moving clients** after they have fallen
 - **lifting/moving clients** safely.

Concerns often raised by their clients’ family members include:

- falls
- driving.

V. Summary

3) Training Topics

Providers suggested several key or essential topics that should be addressed in training:

- experiencing the world through the client's eyes (wearing cotton balls in one's ears, smearing Vaseline on eyeglasses, moving around in a wheelchair) to gain an understanding of and empathy for what clients experience
- interacting with clients
- helping clients and family members safety-proof the home
- food safety
- protecting clients from extreme heat or cold.

4) Dissemination of Information to Providers: Formats and Venues

- Videos and in-service training sessions would be the most accessible formats for providers. (Few had received formal training to work with the elderly).
- Videos and training situations should depict real situations that providers might encounter — combative behavior, awkward lifting or moving of a client, frustration.

VI. Recommendations

While focus group methodology does not lend itself to comparisons across groups or the generalization of participants' comments, a discussion of recurring themes or motifs as well as differences in responses is often a very worthwhile and valid analytical approach. Recurring themes often provide guidance on areas that should be emphasized or addressed, while differences between groups can indicate areas in which health and safety information should be tailored to reach a specific audience. In the sections that follow, both the common themes as well as the differences are further discussed.

1) Sources of Information

An overarching theme to all participants' responses was a desire to consult the person deemed most knowledgeable about their personal health status: their private physician. Even those who had expressed some difficulty talking with their doctors continued to refer to them simply because the doctors "know me and my health." Similarly, local pharmacists who had personal medical information on file were also deemed trustworthy sources of information. Even those who had consulted "ask a doctor" or "ask-a-nurse" hotlines did so in cases where their private doctor could not be reached, such as in an emergency or after hours. Elder care providers shared this sentiment, many stating that they felt more comfortable and assured by consulting supervisor or colleagues who know them and their clients. These findings suggest that providing additional information to physicians, nurses, and agencies might be an effective way of reaching the elderly population and those who care for them.

The local health department was not seen as either an appropriate or expedient source of information by the vast majority of respondents. While lingering stigma about health departments as a resource for the indigent had prevented many participants from consulting them, others were simply unaware of the services such agencies provide. Consequently, increased marketing of local health departments as a source of both information and health care services was suggested by all.

Also of interest, few participants mentioned consulting a book or resource guide for health and safety information. While some mentioned such popular materials as **The 36 Hour Day**, many could not think of any book or manual to which they could turn for health care information. Although respondents felt that health and safety materials such as brochures, manual, pamphlets, etc. were useful and needed sources of information, many felt that currently such information is rarely organized in a concise, easy-to-understand fashion. A number of respondents commented on the fact that often they receive a pamphlet here or a booklet there, and that some type of manual covering a wide range of topics and concerns would be most helpful.

On the other hand, other respondents stated that they preferred to consult health care professionals with their questions, stating that they often doubted whether or not they

VI. Recommendations

would find relevant or applicable health or safety information in health care manuals or pamphlets. Many felt their questions were generally very specific and personal in nature and therefore might not be found in the pages of a health care manual or guide. While these findings highlight the importance of developing comprehensive resource guides, they also indicate that no single guide or even a series of guides can answer all questions or meet all needs. Thus, the need for increasing access to multiple sources of information and improving the quality and quantity of information available from providers becomes extremely important.

2) Main Health Concerns

Although participants across the focus groups shared similar health concerns, there were differences in how participants prioritized these concerns. For example, while safety issues such as driving, cooking, and preventing falls were the most commonly shared concern across focus group participants, elderly participants caring for themselves were most concerned about falls and related hip injuries. On the other hand, cooking and driving safety were more the concerns of those who care for the elderly. As many family members and providers pointed out, these concerns quickly translate into struggles to ensure the safety of older loved ones — especially when driving. Consequently, specific information to assist the elderly in recognizing when the time has come stop driving would benefit both them and those who care for them. In particular, information on the warning signs of declining driving skills or other potential tests or markers of driving ability are greatly needed.

Focus group participants across groups also requested information on common diseases, illnesses, and ailments of the elderly. However, all were quick to stress the importance of not merely describing or explaining certain diseases or illnesses, but providing a breadth of information, ranging from signs and symptoms to diagnosis, prognosis, and treatment. Many felt that too often health and safety materials offered too little information, therefore forcing readers to consult their physicians not for additional information, but for initial understanding and explanation.

Information on interacting with the elderly, especially in light of certain conditions such as Alzheimer's, depression, memory loss, or combative behavior was frequently requested by caregivers, both family members and hired providers alike. Specifically, tips on effective communication and the art of persuasion were considered most critical. Providers also pointed to the need for tailoring such information for providers, depending on the setting in which they work or the health status/condition of their clients.

Lastly, across the groups, participants expressed a strong desire for information on planning for the future, including materials on finding the most appropriate health

VI. Recommendations

insurance plans,, locating quality and affordable health care services, and managing finances. Many participants felt unprepared, in some cases surprised, and in all cases overwhelmed by the cost and responsibility of either growing old or caring for an aging loved one. Thus, materials to help guide and prepare people for this task were frequently suggested. Some respondents also pointed out the need for providing some guidelines on when to consider nursing homes or other assisted living situations.

3) The Role of Public Health Agencies

As previously discussed, the vast majority of focus group participants did not consider the health department an appropriate source of health and safety information and had therefore not sought their assistance in these areas. Yet, participants across the groups felt rather strongly that public health agencies should in fact provide the public with needed health and safety information, especially for the elderly. In particular, participants across the groups suggested that local health departments serve as referral sources or networks, brokering information to callers with an emphasis placed on linking them with *local* and *free* services and resources.

While participants felt strongly that local and state health departments should expand their roles to include information dissemination and referral, the capacity or ability of local health departments to meet this need remains unanswered. It needs to be carefully considered whether or not health and safety materials should recommend that readers contact their local health departments without first equipping such agencies with the information and support necessary to be of assistance. As one reader cautioned, “it should not be made difficult to get needed and important health information, that’s often suggested by the government . . . if it is too hard, people will give up and never do things they need to stay healthy and safe.”

4) Prevention and Public Health Services for the Elderly

Given that the majority of focus group participants feel well served by private physicians, it remains unclear whether or not Federal, state, or local resources should be used to offer prevention and public health services to the elderly. Lingering stigma about receiving “free” or “public” services combined with the apparent widespread access to primary health care among participants suggest that the provision of such services would be ill-advised. A number of participants, however, suggested that public health agencies concentrate their efforts on serving identified pockets of need, those areas of the community where elderly lack access to primary health care. In addition, several participants suggested that health departments provide services such as dental exams, which are often difficult for the elderly to

VI. Recommendations

access due to transportation or financial barriers. Other specific areas of current or growing public health concern such as flu shots, pneumonia shots, mammograms, and TB skin tests were also considered essential services to continue providing and expand, again targeting those elderly with limited financial or transportation resources as well as those living in group settings.

5) Health and Safety Information — Formats and Venues

Visual media such as videos and television (excluding written materials) were clearly the most favored format for providing health and safety information to the elderly and those who care for them. This media allows viewers to access needed information in an often easier-to-understand format, with visual demonstrations of important skills or tasks. Videos in particular allow viewers to access information at their own pace and personal convenience, allowing for opportunities to review important information at a time and location most suitable.

Widespread use of videos and television to disseminate important health and safety information should, however, be carefully considered for their usefulness and appropriateness to the intended audience. Some elderly, for example, may not own videorecorders (VCRs) or televisions or others may find this venue too difficult to follow or understand, preferring print media or even radio. Given the possible and likely range of preferences for (or access to) formats for health and safety information, a multi media approach, taking advantage of printed material, video, television, and radio, is highly recommended.

Participants across the groups also stated that font or print size should be large (especially for older readers), the size and weight of the materials should be moderate to small (again, for older readers), and graphics should be both useful and positive — clearly demonstrating an important piece of health or safety information. Quick reference guides and pages with large, protruding tabs were also considered by most participants an important feature of health and safety materials, citing the importance of making information easy to access. Along similar lines, spiral binding was also preferred by the vast majority of participants; however, many elderly participants suggested the use of notebooks to allow for easy removal or addition of materials — allowing readers to develop notebooks tailored to their specific areas of interest.

Although many participants considered pamphlets and brochures useful formats, they were the least favored. Many participants found the font of most pamphlets too small to read and the size of the pamphlets too easy to misplace or lose. However, 8.5" x 11" pamphlets (the size of standard paper) were considered easier to read and file away in a notebook or folder for future use. These larger-sized pamphlets also allow for additional information to be printed on them as well as the use of larger text and

VI. Recommendations

helpful graphics,.

Participants caring for the elderly (spouses/companions, family members, and providers) were more receptive to attending a health and safety class or seminar than the elderly participants caring for themselves. Elderly participants did not find health and safety classes particularly useful or helpful, stating that they would not feel comfortable attending a class where they did not know anyone or a class held in a building or part of town they were not familiar with. Many elderly participants also felt that transportation to classes would be difficult to arrange. In general, attending a health and safety class conjured up for many elderly participants thoughts of sitting for long periods of time in one place and being “lectured to.” When asked to consider attending a class that would be more interactive in nature — where attendees participated in activities, asked questions, and worked with each other — many had difficulty grasping the concept and thus remained skeptical.

Participants responsible for caring for the elderly, however, found the idea of attending a health and safety class quite intriguing and many stated that they would attend if the class was nearby, held at a convenient time, and inexpensive. In particular, classes or seminars on caring for the elderly, that provided tips on addressing commonly encountered problems or difficult issues, were most desired.

VII. Conclusions

Participants across groups offered a wealth of information, advice, and recommendations for educating and informing the public on health and safety issues for the elderly. While their comments cannot be generalized, participants nonetheless echoed in many ways the sentiments and concerns of the public at large. Despite the format or venue, whether on television, in books, on the radio, in newspapers, or on the Internet, millions of Americans are seeking information on preparing for “old age.”

Although participants’ comments and responses were both numerous and varied, one sentiment rang true for everyone in this study — the importance of being prepared. All participants agreed that the more useful, relevant, and easy-to-understand information they could receive, the more prepared they would be for not only caring for aging loved ones, but caring for themselves when they grow old. As one participant concluded, “Growing old is inevitable; there is nothing we can do to stop that or change it, but how we handle it is still up to us.” The Centers for Disease Control and Prevention is well poised to not only help Americans “handle” old age but prepare for it and enjoy it in as healthy and safe an environment as possible.

APPENDICES

APPENDIX A

FLYERS

ARE YOU OVER THE AGE OF 55?

ARE YOU INTERESTED IN HEALTH CARE AND SAFETY ISSUES FOR OLDER ADULTS?

PLEASE CALL US TO PARTICIPATE IN A FOCUS GROUP DISCUSSION

*We will provide refreshments
and \$25 for your time...*

☎ Call Erika Reed or Antoinette Buchanan at 404-321-3211

Under contract to the Centers for Disease Control and Prevention (CDC), Macro International Inc. is conducting focus groups with older adults to discuss health and safety issues. Focus groups are small informal group discussions, usually of 8-10 people, in which a trained facilitator guides the discussion in order to understand participants' views about a particular topic. There are no right or wrong answers in focus group discussions, because they are about each person's individual opinions and interests.

The purpose of these focus groups is to help CDC understand how it can be more helpful to older people and help you stay healthy and safe. We are interested in finding out more about the types of health and safety information that are currently available, what types of other information might be needed, and the best way to get this information out to older people.

The group will be held on **[DATE]**, **during the day**. When you call us, we will schedule a specific time that is most convenient for you and **WE CAN ALSO ARRANGE FOR A TAXI AS WELL. Refreshments** will also be served at the groups and you will receive \$25 in cash in return for taking time out of your day to share your views with us.

☎ If you are interested in participating or would like more information, please contact **Erika Reed or Antoinette Buchanan** at Macro at **404-321-3211**.

DO YOU CARE FOR AN OLDER SPOUSE OR COMPANION IN YOUR HOME?

ARE YOU INTERESTED IN HEALTH CARE AND SAFETY ISSUES FOR OLDER ADULTS (AGES 55 AND OLDER)?

******WOULD YOU LIKE TO MAKE \$25!!!******

PLEASE CALL US TO PARTICIPATE IN A FOCUS GROUP DISCUSSION

☎ Call Erika Reed or Antoinette Buchanan at 404-321-3211

Under contract to the Centers for Disease Control and Prevention (CDC), Macro International Inc. is conducting focus groups with older adults to discuss health and safety issues. Focus groups are small informal group discussions, usually of 8-10 people, in which a trained facilitator guides the discussion in order to understand participants' views about a particular topic. There are no right or wrong answers in focus group discussions, because they are about each person's individual opinions and interests.

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The group will be held on **[DATE], during the day.** When you call us, we will schedule a specific time that is most convenient for you and **WE CAN ALSO ARRANGE FOR A TAXI AS WELL.** Refreshments will also be served at the groups and you will receive \$25 in cash in return for taking time out of your day to share your views with us.

☎ If you are interested in participating or would like more information, please contact **Erika Reed or Antoinette Buchanan** at Macro at **404- 321- 3211.**

DO YOU CARE FOR AN OLDER FAMILY MEMBER?

**ARE YOU INTERESTED IN HEALTH CARE AND
SAFETY ISSUES FOR ADULTS 55 AND OVER?**

*****WOULD YOU LIKE TO MAKE \$25!!!*****

**PLEASE CONTACT US TO PARTICIPATE IN A
FOCUS GROUP DISCUSSION**

**☎ Call Erika Reed or Antoinette Buchanan
at 404-321-3211**

Under contract to the Centers for Disease Control and Prevention (CDC), Macro International Inc. is conducting focus groups with family members who care for an older relative, companion, or spouse to discuss health and safety issues. We will also be conducting focus groups with older adults and elder care providers, in both urban and rural settings throughout Georgia. Focus groups are small in formal group discussions, usually of 8- 10 people, in which a trained facilitator guides the discussion in order to understand participants' views about a particular topic. There are no right or wrong answers in focus group discussions, because they are about each person's individual opinions and interests.

The purpose of these focus groups is to help CDC understand how it can be more helpful to older people, their families, and providers who care for older people. We are interested in finding out more about the types of health and safety information that are currently available, what types of additional information might be needed, and which format would be most useful to older people and the people who care for them.

The focus groups will be held on [DATE], in the early evening, and will last about 90 minutes. A specific time will be arranged depending on what is most convenient for participants. Refreshments will be served, and you will receive \$25 in cash for taking time out of your day to share your views with us.



If you are interested in participating or would like additional information, please contact Erika Reed or Antoinette Buchanan at Macro, 404-321-3211.

**DO YOU PROVIDE CARE, ASSISTANCE, OR
COMPANIONSHIP TO AN OLDER ADULT?**

**ARE YOU INTERESTED IN HEALTH CARE AND
SAFETY ISSUES FOR ADULTS 55 AND OVER?**

WOULD YOU LIKE TO MAKE \$25!!!

**PLEASE CONTACT US TO PARTICIPATE IN A
FOCUS GROUP DISCUSSION THIS SUMMER**

**☎ Call Erika Reed or Antoinette Buchanan at
404-321-3211**

Under contract to the Centers for Disease Control and Prevention (CDC), Macro International Inc. is conducting focus groups with elder care providers to discuss health and safety issues. We will also be conducting focus groups with older adults and their families, in both urban and rural settings throughout Georgia. Focus groups are small informal group discussions, usually of 8-10 people, in which a trained facilitator guides the discussion in order to understand participants' views about a particular topic. There are no right or wrong answers in focus group discussions, because they are about each person's individual opinions and interests.

The purpose of these focus groups is to help CDC understand how it can be more helpful to older people, their families, and people who care for the elderly. We are interested in finding out more about the types of health and safety information and training that are currently available, what types of additional information might be needed, and which format would be most useful to older people and to those who provide care for the elderly.

The focus group will be held [DATE], in the early evening and last for about 90 minutes. A specific time will be arranged depending on what is most convenient for participants. Refreshments will be served, and you will receive \$25 in cash for taking time out of your busy schedule to share your views with us.



*If you are interested in participating or would like additional information, please contact
Erika Reed or Antoinette Buchanan at Macro, 404-321-3211.*

APPENDIX B
SCREENING FORMS

ELDER CARE HEALTH AND SAFETY FOCUS GROUPS
TELEPHONE SCREENER FOR ELDERLY

Thanks for calling. I'll give you some information about where and when the focus groups will be held, and then I'll need to ask you a few questions. This should take about 5 minutes.

What kind of living arrangements do you have?

- independently (their own house or apartment)
- with a family member
- in an senior living facility (*If yes, find out what type of facility it is--assisted, skilled nursing facility, no assistance, etc.*)

If the caller lives in a skilled nursing home or some other type of facility which provides a lot of assistance, thank them for calling and inform them that unfortunately they do not qualify for the study.

For callers who live independently, do you receive any type of care or assistance in your home?

- housekeeping/household chores (cleaning, laundry, dishes, etc.)
- cooking (can include Meals on Wheels)
- transportation
- personal care (bathing, oral care, hair care, etc.)
- companionship
- other (please describe) _____

Who provides this assistance?

- family
- friends or neighbors
- home aide or companion (hired person)
- volunteer group (church or other civic organization)

The focus group will be held at the [FILL IN LOCATION] The group will start at [FILL IN TIME] and will last until [FILL IN TIME] at the latest. We will be serving refreshments, and you will receive \$25 for participating.

Are you going to need any assistance with transportation (a cab, MARTA fare, etc.)?

Where can I reach you to confirm these arrangements the day before the group? Is it OK to call you at work? Telephone:

I can fax or mail you something confirming these details, if you'd like. Fax:

Mailing Address:

Please call me at 321-3211 if your plans change, so that we can invite someone from the waiting list to attend instead. Again, we look forward to seeing you on [FILL IN DATE].

ELDER CARE HEALTH AND SAFETY FOCUS GROUPS
TELEPHONE SCREENER FOR ELDERLY WHO CARE FOR ELDERLY

Thanks for calling. I'll give you some information about where and when the focus groups will be held, and then I'll need to ask you a few questions. This should take about 5 minutes.

How long have you been taking care of your spouse or companion?

_____ months
_____ years

Does your spouse or companion share a household with you? _____

If no, where does he or she live?

_____ independently (their own house or apartment)
_____ in an assisted living facility (*If yes*, find out if the family member provides any type of assistance to the family member or if the facility handles all of that)

If the family member does not provide much assistance but the facility does, thank them for calling and inform them that unfortunately they do not qualify for our study.

How old is your spouse or companion?

_____ years

What type of help or assistance, if any, have you (or do you) provide for your spouse or companion?

_____ housekeeping (cleaning, laundry, dishes, etc.)
_____ cooking
_____ transportation
_____ personal care (bathing, oral care, hair care, etc.)
_____ companionship
_____ other (please describe) _____

The focus group will be held at the: [FILL IN LOCATION] The group will start at [FILL IN TIME] and will last until [FILL IN TIME] at the latest. We will be serving refreshments, and you will receive \$25 for participating.

Are you going to need any assistance with transportation (a cab, bus or MARTA fare)?

Where can I reach you to confirm these arrangements the day before the group? Is it OK to call you at work? Telephone:

I can fax or mail you something confirming these details, if you'd like. Fax:

Mailing Address:

Please call me at 321-3211 if your plans change, so that we can invite someone from the waiting list to attend instead. Again, we look forward to seeing you on [FILL IN DATE]

ELDER CARE HEALTH AND SAFETY FOCUS GROUPS
TELEPHONE SCREENER FOR FAMILY MEMBERS

Thanks for calling. I'll give you some information about where and when the focus groups will be held, and then I'll need to ask you a few questions. This should take about 5 minutes.

How long have you been taking care of your older family member?

____ months
____ years

Does your family member share a household with you? _____

If no, where does he or she live?

____ independently (their own house or apartment)
____ in an assisted living facility (*If yes*, find out if the family member provides any type of assistance to the family member or if the facility handles all of that)

If the family member does not provide much assistance, thank them for calling and inform them that unfortunately they do not qualify for our study.

How old is your family member?

____ years

What type of help or assistance, if any, have you (or do you) provide for your family member?

____ housekeeping (cleaning, laundry, dishes, etc.)
____ cooking
____ transportation
____ personal care (bathing, oral care, hair care, etc.)
____ companionship
____ other (please describe) _____

The focus group will be held at the, [FILL IN LOCATION] The group will start at [FILL IN TIME] and will last until [FILL IN TIME] at the latest. We will be serving refreshments, and you will receive \$25 for participating.

Where can I reach you to confirm these arrangements the day before the group? Is it OK to call you at work? Telephone:

I can fax or mail you something confirming these details, if you'd like. Fax:

Mailing Address:

Please call me at 321-3211 if your plans change, so that we can invite someone from the waiting list to attend instead.

Again, we look forward to seeing you on [FILL IN DATE]

ELDER CARE HEALTH AND SAFETY FOCUS GROUPS
TELEPHONE SCREENER FOR ELDER CARE PROVIDERS

Thanks for calling. I'll give you some information about where and when the focus groups will be held, and then I'll need to ask you a few questions. This should take about 5 minutes.

How long have you been providing care for the elderly?

_____ months
_____ years

Have you had any training in elder care *before you* began caring for the elderly?

_____ yes
_____ no

Where did you receive this training?

How old are the clients that you tend to care for?

_____ years

What is your case load? (i.e. the total number of clients you currently care for)

How many hours a week do you spend with each client?

What types of services do you generally provide?

_____ housekeeping (cleaning, laundry, dishes, etc.)
_____ cooking
_____ transportation
_____ personal care (bathing, oral care, hair care, etc.)
_____ companionship
_____ other (please describe) _____

The focus group will be held at the [FILL IN LOCATION] The group will start at [FILL IN TIME] and will last until [FILL IN TIME] at the latest. We will be serving refreshments, and you will receive \$25 for participating.

Where can I reach you to confirm these arrangements the day before the group? Is it OK to call you at work? Telephone:

I can fax or mail you something confirming these details, if you'd like. Fax:

Mailing Address:

Please call me at 321-3211 if your plans change, so that we can invite someone from the waiting list to attend instead.

Again, we look forward to seeing you on [FILL IN DATE].

APPENDIX C
MODERATOR'S GUIDES

ELDERLY FOCUS GROUP
DISCUSSION GUIDE

Submitted to:

Centers for Disease Control and Prevention

by:

Macro International Inc.

June 13, 1997

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Total Focus Group Time: approximately 90 minutes

I. BACKGROUND AND INTRODUCTIONS (5- 10 minutes)

Objectives:

- Put participants at ease
- Explain purpose of discussion and focus group process

Moderator will introduce herself, welcome participants, invite them to enjoy refreshments, and distribute tent cards and consent forms.

Purpose:

As you know from the phone call inviting you to participate, this discussion is part of a study being conducted by the Centers for Disease Control and Prevention. The purpose of the study is to learn more about what you think is important in terms of preventing disease and injury and promoting healthy behaviors among people your age. We are also conducting similar discussion groups (both here in Atlanta and in rural areas) with family members and providers to also find out what they think is important in keeping people safe and healthy as they get older.

What you share with us today [tonight] will assist CDC in determining topics of interest and needs for the development of policies, guidelines, and manuals regarding health and safety for older people. We thank you in advance for coming out and sharing your opinions and ideas with us.

Procedures:

Before I ask you to introduce yourselves, I want to explain how this will work. I'm going to ask a series of questions to launch the discussion. Anyone can speak out; you don't need to wait for me to call on you. But please keep in mind that we have a lot to cover in our brief time together, so please don't be offended if I interrupt you to move on. It's important for us to hear from everyone, and to cover the topics in equal depth.

I also want to point out that there's no such thing as a wrong answer to these questions. We're interested in your opinions.

We are tape-recording this session, even though my colleague is taking notes as well. I hope that the tape recorder won't make anyone uncomfortable. We don't expect to get into any personal or controversial topics, but if we do, rest assured that we will not report on any comments by name. The recorder is purely for accuracy in our reporting. Please try to speak loudly and clearly, and one at a time.

Moderator will briefly review consent form with participants.

Introductions:

Moderator will ask participants to introduce themselves.

II. HEALTH AND SAFETY INFORMATION (20 minutes)

One of the topics of interest to CDC is the kinds of information you have available to you, and what other kinds of materials might be helpful.

1. Think back to a recent question you've had about your health or safety. Who did you turn to for information?

Probes:

- doctor or nurse
- other elderly (family or friends)
- local health department
- senior citizen's center or organization
- brochures or handbooks

Is that your usual source of information?

Is there anyone else that you might call or contact?

2. What situations or topics have you called someone about in the past, or tried to get more information about?

Probes:

- preventing the spread of germs (handwashing, cleaning, etc.)
- injury prevention (prevention of falls, safetyproofing, etc)
- CPR/ first aid
- nutrition
- disabilities (physical or mental)
- information on specific diseases or illness (e.g. signs and symptoms of diabetes, heart disease, osteoporosis, etc.)

3. How often do you find you need health and safety information but it is not readily available?

4. What other kinds of general health care or safety information would you find helpful?
- warning signs of disease
 - preventing falls or injuries at home (safetyproofing your home)
 - nutrition and healthy eating
 - exercise and physical fitness
 - smoking cessation
 - finding quality health care (e.g. home-based, nursing homes, hospitals, etc.)
 - information about important vaccinations (flu shots, tetanus boosters, Hep B)
 - mental health (e.g. bereavement issues, dealing with terminal illness, Alzheimers, etc.)

5. What format would you like this information in? (*see examples*)

Probes:

- poster/factsheet
- manual/handbook
- video
- newsletter
- brochure/flyer

6. If some kind of health and safety class were offered at a local hospital, clinic, or health department a couple times a year, would you go?

Why or why not?

Probes:

- transportation
- potential costs
- “just not interested”
- “don’t like going to hospitals or clinics”

7. Would it make a difference if it were held somewhere else like at a local community center, senior citizen’s center, a local church, local library, local school, or maybe at your apartment complex or living facility?

8. Where could a class or session be held that was most convenient or comfortable for you?

What about for friends, family, or neighbors who are your age?

III. HEALTH AND SAFETY COMMUNICATION WITH PROVIDERS (15 minutes)

1. Have you discussed general health and safety issues with your doctor or nurse? What kinds of things did you talk about?
2. What kinds of things do you think your doctor or nurse worries about when it comes to your health?

Probes:

- nutrition/diet
- exercise and physical fitness
- smoking
- medication compliance
- injuries (falling, car accidents, etc.)

Do you worry about these things too?

3. Do you ever write down your questions or concerns to give to your doctor or ask them about when you have an appointment?
4. Have you ever received health and safety *materials* from your doctor or nurse? What kinds of materials did you receive?

Probes:

- brochure/pamphlet
- video
- handbook or manual
- list of resources (places to call or go for more help or information)

Which information or materials did you find most useful?

Which did you (or do you) find most difficult to understand or to use?

why?

Probes:

- very complex (e.g. medical terms, complicated concepts)
- “doctor or nurse did not explain it well”
- “did not seem to apply to me”...*probe further*

- race/cultural issues. *..probe further*
- gender *issues...probe further*
- finances (“I did not have the money to buy recommended foods or medicines, etc.)
- feeling rushed in the visit (“not enough time to talk about it”)

5. Are there materials that you wish you had, to address a specific question or concern? What kinds?

If any of the following are not mentioned:

What about information on topics such as:

- disease prevention (flu, pneumonia, food poisoning)
- nutrition
- smoking cessation
- preventing falls and injuries at home
- violence or abuse prevention
- mental health issues

IV. PUBLIC HEALTH ROLE (15 minutes)

As the US population ages, CDC has been receiving more and more requests for information on basic health issues and disease prevention procedures. Thus, CDC would like to reach older people with the information they need to stay healthy and safe. Let’s spend the rest of our time together talking about the potential role of health departments and CDC in encouraging and promoting your health and safety.

1. Some of you have mentioned the health department as a source of information. Why did you call them?

Probes:

- to answer a specific question or give advice
- to provide educational materials such as brochures, pamphlets, or handbooks
- to make referrals (get information about local resources or programs)
- to receive a service (immunizations, flu shots, vision screening, etc.)

What was their response? Was it helpful?

1a. Or, no one mentioned calling the health department for information about health or safety issues? Why not?

- “just did not think about it”
- “did not think the health department could help me”
- “health department is not for health care questions”
- “health department is only for the poor”

2. Do you know of friends or family who use the health department?

3. What are some ways that the health department could be more helpful to you?

- hotline
- newsletter/updates on health and safety
- lending library for health and safety videos
- training sessions or classes
- screening services (diabetes, blood pressure, vision, hearing, dental, etc.)

V. PREVENTION AND PUBLIC HEALTH SERVICES FOR ELDERLY (15 minutes)

1. When we talk about prevention we mean preventing diseases or finding out about a disease early enough to keep it from becoming too serious. If services to prevent diseases or illness could be offered to people your age, which services would you consider most important?

- dental check ups
- immunizations (flu shots, tetanus boosters, Hepatitis B vaccinations, etc.)
- vision and hearing screenings
- blood pressure checks
- diabetes screening
- nutrition
- smoking cessation information

2. If you think about yourself, your spouse, (if applicable) or other people your age, what would be the best way of getting these services out to older people?

- mobile vans
- health fair at local churches
- local health department and/or clinic
- local senior citizen’s center
- a health fair through their living facility (e.g. their apartment complex, their assisted living facility, etc.)

3. What would be the reasons why you **would not** take advantage of such services if they were available?

Probes:

- costs
- transportation (if not very close by)
- access (physical impairment or disability issues)
- fear or distrust of medical care

4. What about other people you know who are your age, why wouldn't they take advantage of these services?

VI. MATERIALS REVIEW AND CONCLUSION (15 minutes)

In an effort ensure that health and safety information is as useful and relevant as possible, I would like you to spend the final 10 to 15 minutes of our discussion reviewing the materials I am passing around the table. Please think about the format (size, shape, color, print size, etc.) of these materials and tell me what you like and dislike most about what you are reading.

Those are all the questions I have. Does anyone have any other comments about any of the topics we've discussed--something you've thought of while we were talking about other things? Please feel free to call me at --- if you think of something you'd like us to know about in the next few days.

Thanks again for taking the time to give us your opinions. Please remember to sign the participant list and receive your honorarium from me before you leave.

ELDERLY WHO CARE FOR ELDERLY
FOCUS GROUP
DISCUSSION GUIDE

Submitted to:

Centers for Disease Control and Prevention ...

by:

Macro International Inc.

June 13, 1997

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Total Focus Group Time: approximately 95 minutes

I. BACKGROUND AND INTRODUCTIONS (5 minutes)

Objectives:

- Put participants at ease
- Explain purpose of discussion and focus group process

Moderator will introduce herself, welcome participants, invite them to enjoy refreshments, and distribute tent cards and consent forms.

Purpose:

As you know from the phone call inviting you to participate, this discussion is part of a study being conducted by the Centers for Disease Control and Prevention. The purpose of the study is to learn more about what you think is important in terms of preventing disease and injury and promoting healthy behaviors among people your age. We are also conducting similar discussion groups (both here in Atlanta and in rural areas) with older people and providers to also find out what they think is important in keeping people healthy and safe as they get older.

What you share with us today [tonight] will assist CDC in determining topics of interest and needs for the development of policies, guidelines, and manuals regarding health and safety for older people. We thank you in advance for coming out and sharing your opinions and ideas with us.

Procedures:

Before I ask you to introduce yourselves, I want to explain how this will work. I'm going to ask a series of questions to launch the discussion. Anyone can speak out; you don't need to wait for me to call on you. But please keep in mind that we have a lot to cover in our brief time together, so please don't be offended if I interrupt you to move on. It's important for us to hear from everyone, and to cover the topics in equal depth.

I also want to point out that there's no such thing as a wrong answer to these questions. We're interested in your opinions.

We are tape-recording this session, even though my colleague is taking notes as well. I hope that the tape recorder won't make anyone uncomfortable. We don't expect to get into any personal or controversial topics, but if we do, rest assured that we will not report on any comments by name. The recorder is purely for accuracy in our reporting. Please try to speak loudly and clearly, and one at a time.

Moderator will briefly review consent form with participants.

Introductions:

Moderator will ask participants to introduce themselves and briefly describe the type of assistance they provide to their spouse or companion and how long they have caring for this person.

II. HEALTH AND SAFETY INFORMATION--SPOUSE/COMPANION (15-20 minutes)

One of the topics of interest to CDC is the kinds of information you have available to you, and what other kinds of materials might be helpful. Of particular interest to us, is what kinds of information you have and need, as an older person who cares for a sick companion or spouse.

1. What are some of the main health concerns you have for your spouse or companion, what kinds of health or safety issues are you dealing with?
2. If you have a health or safety question regarding the care of your companion or spouse who do you usually call or where do you go to get more information?

Probes:

- doctor or nurse
- other people your age (family or friends)
- health department
- senior citizen's organization or center (e.g. Red Cross, AARP, etc.)
- social worker
- library

Is that your usual source of information?

Is there anyone else you might call or any other place you might go?

3. What situations or topics have you called someone about in the past, or tried to get more information about?

Probes:

- handwashing, cleaning, (preventing the spread of germs)
- personal care (bathing, oral care, etc.)
- injury prevention (prevention of falls, safetyproofing, etc)
- CPR/ first aid
- nutrition
- disabilities (physical or mental)
- mental health issues (depression, mortality issues, Alzheimers, etc.)

- signs and symptoms of diseases
4. How often do you find you need health and safety information but it is not readily available?
 5. Thinking back to when you *first began* caring for your spouse or companion, is there any health and safety information that you think would have been important or helpful to have?
 6. Are there any other kinds of general health care or safety information you would find helpful for caring for your spouse or companion?
 - warning signs of disease,
 - preventing falls or injuries at home (safetyproofing your home)
 - nutrition and healthy eating
 - exercise and physical fitness
 - smoking cessation
 - finding quality health care (e.g. home-based, nursing homes, hospitals, etc.)
 - information about important vaccinations (flu shots, tetanus boosters, Hep B)
 - mental health (e.g. dealing with terminal illness, Alzheimers, etc.)
 - food preparation/food safety

What format would you like this information in?

Probes:

- poster
 - manual or handbook
 - video
 - brochure/flyer
 - newsletter
7. If some kind of health and safety class were offered, specifically for older people who care for sick companions or spouses, at a local hospital, clinic, or the health department, would you go?

Why or why not?

Probes:

- transportation
- potential costs
- “just not interested”
- time

8. Would it make a difference if it were held somewhere else like at a local community center, senior citizen's center, a local church, local library, local school, job, or maybe at your apartment complex or living facility?
9. Where could a class or session be held that was most convenient or comfortable for you?
10. What about for friends, family, or neighbors that are your age?

III. PERSONAL HEALTH AND SAFETY INFORMATION (15 minutes)

CDC is very interested in learning about the different types of information you could use to keep you safe and healthy while you are caring for your spouse or companion.

1. **Who** do you call or where do you go to get **personal** information about staying healthy and safe?

Probes:

- **personal** doctor or nurse
- other elderly (family or friends)
- local health department
- senior citizen's center or organization
- brochures or handbooks

2. What situations or topics have you called someone about in the past, or tried to get more information about?

Probes:

- injury prevention (prevention of falls, safetyproofing, etc)
- nutrition
- information on specific diseases or illness (e.g. signs and symptoms of diabetes, heart disease, osteoporosis, etc.)
- exercise and physical fitness
- mental health (depression, terminal illness, etc.)

3. Have you ever received any *materials* from your doctor or nurse regarding *your personal health and safety*? What kinds of materials did you receive?

- brochure/pamphlet
- video
- handbook/manual
- list of resources (places to call or go for more help or information)

4. Which *information or materials* did you find most useful?

5. Which did you (or do you) find most difficult to understand or to use?

why?

Probes:

- very complex (e.g. medical terms, complicated concepts)
- “doctor or nurse did not explain it well”
- “did not seem to apply to me”...*probe further*
- race/cultural *issues...probe further*
- gender issues...*probe further*
- finances (“I did not have the money to buy recommended foods or medicines,” etc.)
- felt rushed during visit (“did not have the time to ask questions, h/she did not have the time to really explain it to me”)

6. As an older person caring for a sick companion or spouse, are there any other specific topics or issues that you would like information on to help keep YOU healthy and safe?

- information on preventing personal injuries while caring for others
- nutrition (“meeting both of our nutritional needs”)
- immunizations
- preventing the spread of germs in the house
- mental health (depression, stress, mortality issues)
- smoking cessation

7. What would be the best format for this information or materials?

- handbook/manual
- video
- brochures/flyers
- posters/factsheets
- newsletter

Iv. HEALTH AND SAFETY COMMUNICATION--PROVIDER (20 minutes)

1. Coming back to something we talked a little bit about when we first started, if you think about all of the different things you do to care for your spouse or companion, what kinds of health and safety concerns do you have?

Probes:

- nutrition/diet
- exercise and physical fitness
- smoking
- medication compliance
- injuries (falls, accidents, etc.)
- mental health (depression, mortality issues, stress)
- driving safety

Is your spouse or companion also worried about these things?

2. Do you discuss general health and safety issues with your spouse or companion?

Are there any health and safety issues that are hard to explain to them? why?

Probes:

- level of information is too complex
- gender issues (e.g. “my grandfather does not want to cook or clean”)
- age or generational issues
- mental health issues (Alzheimers, dementia, etc.)
- driving safety

3. Have you ever talked to your (or your spouse’s or companion’s) doctor or nurse about any health or safety issues you have related to taking care of your family member? What did you talk about?

Probes:

- nutrition/diet
- exercise and physical fitness
- smoking
- medication compliance
- driving safety

4. What kinds of things do you think your doctor or nurse worries about when it comes to ***you taking care of your spouse or companion?***

Do you share these concerns?

5. Have you ever received any health and safety information from your doctor or nurse on ***taking care of your spouse or companion?*** What kinds of materials or information?

Which information did you find most useful?

6. Which information did you (or do you) find most difficult to understand or to use?

why?

Probes:

- very complex (e.g. medical terms, complicated concepts)
 - “doctor or nurse did not explain it well”
 - “did not seem to apply to me”...***probe further***
 - race/cultural issues...***probe further***
 - gender issues...***probe further***
 - finances (“I did not have the money to buy recommended foods or medicines, etc.)
 - did not have the time (“too rushed during clinic visit”)
7. Are there materials or information that you wish you had, to address a specific question or concern? What kinds?

If any of the following are not mentioned:

What about information on topics such as:

- disease prevention (flu, pneumonia, food poisoning)
- nutrition
- preventing falls and injuries at home
- mental health (depression, stress, mortality issues)
- smoking cessation

V. PUBLIC HEALTH ROLE (15 minutes)

As the US population ages, CDC has been receiving more and more requests for information on basic health issues and disease prevention procedures. Thus, CDC would like to reach older people with the information they need to stay healthy and safe. Let's spend the rest of our time together talking about the potential role of health departments and CDC in promoting both your health and safety and helping you care for your spouse or companion.

1. Some of you have mentioned the health department as a source of information for helping you care for your spouse or companion. Why did you call them?

- to answer a specific question or give advice
- to provide educational materials such as brochures, pamphlets, or handbooks
- to make referrals (get information about local resources or programs)
- to receive a service (immunizations, flu shots, vision screening, etc.)

What was their response? Was it helpful?

1a. *Or*, no one mentioned calling the health department for information about health or safety issues? Why not?

- "just did not think about it"
- "did not think the health department could help me"
- "health department is not for health care questions"
- "health department is only for the poor or for diseases"

2. Do you know of friends or family who use the health department as a source of information?

3. What are some ways that the health department could be more helpful to you?

- hotline
- newsletter/updates on health and safety
- lending library for health and safety videos
- training sessions or classes
- screening services (diabetes, blood pressure, vision, hearing, dental, etc.)

VI. PREVENTION AND PUBLIC HEALTH SERVICES FOR ELDERLY (10 minutes)

1. When we talk about prevention we mean preventing diseases or finding out about a disease early enough to keep it from becoming too serious. If services to prevent diseases or illness could be offered to people your age, which services would you consider most important?

- dental check ups
- immunizations (flu shots, tetanus boosters, Hepatitis B vaccinations, etc.)
- vision and hearing screenings
- blood pressure checks
- diabetes screening
- smoking cessation
- nutrition

2. If you think about yourself, your spouse, (if applicable) or other people your age, what would be the best way of getting these services out to older people?

- mobile vans
- health fair at local churches
- local health department and/or clinic
- local senior citizen's center
- a health fair through their living facility (e.g. their apartment complex, their assisted living facility, etc.)

3. What would be the reasons why you *would* not take advantage of such services if they were available?

Probes:

- costs
- transportation
- access (physical impairment or disability issues)
- fear or distrust of medical care

4. What about other people you know who are your age, why wouldn't they take advantage of these services?

VII. MATERIALS REVIEW AND CONCLUSION (15 minutes)

In an effort ensure that health and safety information is as useful and relevant as possible, I would like you to spend the final 10 to 15 minutes of our discussion reviewing the materials I **am** passing around the table. Please **think** about the format (size, shape, color, print size, etc.) of these materials and tell me what you like and dislike most about what you are reading.

Those are all the questions I have. Does anyone have any other comments about any of the topics we've discussed--something you've thought of while we were talking about other things? Please feel free to call me at ---- if you think of something you'd like us to know about in the next few days.

Thanks again for taking the time to give us your opinions. Please remember to sign the participant list and receive your honorarium from me before you leave.

FAMILY MEMBERS WHO CARE FOR ELDERLY

FOCUS GROUP

DISCUSSION GUIDE

Submitted to:

Centers for Disease Control and Prevention

by:

Macro International Inc.

June 13, 1997

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Total Focus Group Time: approximately 95 minutes

I. BACKGROUND AND INTRODUCTIONS (5- 10 minutes)

Objectives:

- Put participants at ease
- Explain purpose of discussion and focus group process

Moderator will introduce herself, welcome participants, invite them to enjoy refreshments, and distribute tent cards and consent forms.

Purpose:

As you know from the phone call inviting you to participate, this discussion is part of a study being conducted by the Centers for Disease Control and Prevention. The purpose of the study is to learn more about what you think is important in terms of preventing disease and injury and promoting healthy behaviors among older people. We are also conducting similar discussion groups (both here in Atlanta and in rural areas) with older people and providers to also find out what they think is important in keeping people safe and healthy as they get older.

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Procedures:

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Moderator will briefly review consent form with participants.

Introductions:

Moderator will ask participants to introduce themselves and briefly describe the type of assistance they provide and how long they have caring for this person.

II. HEALTH AND SAFETY INFORMATION (20 minutes)

One of the topics of interest to CDC is what kinds of information you have available to you as a family member who cares for an older family member.

1. What are some of the main health concerns you have for your older family member, what kinds of health or safety issues are you dealing with?
2. If you have a health or safety questions regarding the care of your older family member, who do you usually call or where do you go for information?

Probes:

- ***personal*** doctor or nurse
- ***your family member's*** doctor or nurse
- family or friends
- health department
- senior citizen's organization or center (e.g. Red Cross, AARP, etc.)
- social worker
- library

Is this your usual source of information? Is there anyone else you might call or any other place you might go to for help?

3. What situations or topics have you called someone about in the past or tried to get more information about?

Probes:

- handwashing, cleaning, (preventing the spread of germs)
- hygiene (bathing, oral care, etc.)
- injury prevention (prevention of falls, safetyproofing, etc)
- CPR/ first aid
- nutrition
- disabilities (physical or mental)
- mental health issues (depression, terminal illness, bereavement)
- signs and symptoms of disease

4. How often do you find you need health and safety information but it is not readily available?

What are some examples?

5. Thinking back to when you **first began** caring for your family member or friend, is there any health and safety information that you think would have been important or helpful to have?

6. Are there any other kinds of general health care or safety information you would find helpful for caring for your elderly family member or friend?

- warning signs of disease
- preventing falls or injuries at home (safetyproofing your/their home)
- nutrition and healthy eating
- exercise and physical fitness
- smoking cessation
- finding quality health care (e.g. home-based, nursing homes, hospitals, etc.)
- information about important vaccinations (flu shots, tetanus boosters, Hep B)
- mental health (e.g. dealing with terminal illness, Alzheimers, etc.)
- food preparation/food safety

7. What format would you like this information in?

Probes:

- poster
- manual or handbook
- video
- brochure/flyer
- newsletter

8. If there were some kind of health and safety class (like at the health department or a local hospital or clinic) specifically for family members who care for an elderly family member or friend, would you go?

Why or why not?

Probes:

- transportation
 - potential costs
 - time
 - ‘just not interested’
9. Would it make a difference if it were held somewhere else like at a local community center, senior citizen’s center, a local church, local library, local school, or maybe at your job?
10. Where could a class or session be held that was most convenient or comfortable for you?
11. What about for friends, family, or neighbors that are in a similar situation?

III. PERSONAL HEALTH AND SAFETY INFORMATION (15 minutes)

Caring for a elderly family member or friend can be very physically, emotionally, and financially burdensome. Thus, CDC is very interested in learning about the different types of information you could use to preserve your own well-being as well as that of your family member or friend.

1. As a family member for an elderly family member or friend, are there any specific topics or issues that you would like information on to help keep **YOU** healthy and safe?
- information on preventing personal injuries while caring for others
 - nutrition (“meeting multiple nutritional needs”)
 - preventing the spread of germs in the house
 - personal mental health (bereavement, coping with terminal illness in a family member, stress, etc.)
2. What would be the best format for this information or materials?
- handbook/manual
 - video
 - brochures/flyers
 - posters/factsheets
 - newsletter

3. Have you ever received any information on keeping yourself healthy and safe?

What kinds or types of information did you receive?

Probes:

- communication skills (how to communicate with my elderly family member)
- nutrition (meeting the nutritional needs for my family and my elderly family member)
- family issues (maintaining a stable family environment, maintaining your marriage, transitioning a new family member into your home, etc.)
- mental health issues

IV. HEALTH AND SAFETY COMMUNICATION (20 minutes)

1. Coming back to something we talked a little bit about when we first started, if you think about all of the different things you do to care for your older family member or friend, what kinds of health and safety concerns do you have?

Probes:

- nutrition/diet
- exercise and physical fitness
- smoking
- medication compliance
- injuries (such as falls)
- driving safety

Is your family member also worried about these things?

2. Do you discuss general health and safety issues with your family member?

Are there any health and safety issues that are hard to explain to them?

why?

Probes:

- level of information is too complex
- gender issues (e.g. “my grandfather does not want to cook or clean”)
- age or generational issues
- mental health issues (Alzheimers, dementia, etc.)

3. Are there any types of information or materials that would be helpful to share with them?
4. Have you ever talked to your (or your family member's) doctor or nurse about any health or safety issues related to taking care of your family member? What did you talk about?

Probes:

- nutrition/diet
- exercise and physical fitness
- smoking
- medication compliance
- injuries (falls, accidents, etc.)
- mental health (depression, terminal illness, bereavement, etc.)

5. What kinds things do you think your doctor or nurse worries about when it comes to you caring for your family member?

Do you share these concerns?

6. Have you ever received any health and safety information from your doctor or nurse on taking care of your family member? What kinds of material or information did you receive?

Which information did you find most useful? Why?

7. Which information did you find most difficult to use or understand?

why?

Probes:

- very complex (e.g. medical terms, complicated concepts)
- "doctor or nurse did not explain it well"
- "did not seem to apply to me"...**probe further**
- race/cultural **issues...probe further**
- gender **issues...probe further**
- finances ("I did not have the money to buy recommended foods or medicines, etc.)
- did not have the time ("too rushed during clinic visit")

8. We talked about this a little bit before, but are there any other types of information or materials that you wish you had, maybe to address a specific question or concern?

Probes:

- disease prevention (immunizations, food poisoning, etc.)
- nutrition
- preventing falls and injuries/safetyproofing
- mental health (depression, stress, mortality issues)
- smoking cessation
- driving safety

V. PUBLIC HEALTH ROLE (15 minutes)

As the US population ages, CDC has been receiving more and more requests for information on basic health issues and disease prevention procedures. Thus, CDC would like to reach more people with the information they need to stay healthy and safe. Let's spend the rest of our time together talking about the potential role of health departments and CDC in encouraging and promoting both your health and safety and in helping you care for your family member.

1. Some of you mentioned the health department as a source of information for helping you care for your family member(s). Why did you call them?

Probes:

- to answer a specific question or give advice
- to provide educational materials such as brochures, pamphlets, or handbooks
- to make referrals (get information about local resources or programs)
- to receive a service (immunizations, flu shots, vision screening, etc.)

What was their response? Was it helpful?

- 1a.* Or, no one mentioned calling the health department for information about caring your family member or friend? Why?

- “just did not think about it”
- “did not think the health department could help me”
- “health department is not for health care questions”
- “health department is only for the poor or for diseases”

2. Do you know of friends or family who use the health department as a resource?

3. What are some ways that the health department could be more helpful to you?
- hotline
 - newsletter/updates on health and safety
 - lending library for health and safety videos
 - training sessions or classes
 - screening services for elderly (diabetes, blood pressure, vision, hearing, dental, etc.)

VI. PREVENTION AND PUBLIC HEALTH SERVICES FOR ELDERLY (10 minutes)

1. When we talk about prevention we mean preventing diseases or finding out about a disease early enough to keep it from becoming too serious. If services to prevent diseases or illness could be offered to your family member, which services would you consider most important?
- dental check ups
 - immunizations (flu shots, tetanus boosters, Hepatitis B vaccinations, etc.)
 - vision and hearing screenings
 - blood pressure checks
 - diabetes screening
 - nutrition
 - smoking cessation
2. What would be the best way of getting these services to the elderly?
- mobile vans
 - health fair at local churches
 - local health department and/or clinic
 - local senior citizen's center
 - a health fair through their living facility (e.g. their apartment complex, their assisted living facility, etc.)
3. What would be the reasons why you and your family member *would not* take advantage of such services if they were available?

Probes:

- costs
- transportation
- access (physical impairment or disability issues)
- time
- fear or distrust of medical care

VII. MATERIALS REVIEW AND CONCLUSION (15 minutes)

In an effort ensure that health and safety information is as useful and relevant as possible, I would like you to spend the final 10 to 15 minutes of our discussion reviewing the materials I am passing around the table. Please think about the format (size, shape, color, print size, etc.) of these materials and tell me what you like and dislike most about what you are reading.

Those are all the questions I have. Does anyone have any other comments about any of the topics we've discussed--something you've thought of while we were talking about other things? Please feel free to call me at ---- if you think of something you'd like us to know about in the next few days.

Thanks again for taking the time to give us your opinions. Please remember to sign the participant list and receive your honorarium from me before you leave.

PROVIDER FOCUS GROUP

DISCUSSION GUIDE

Submitted to:

Centers for Disease Control and Prevention

by:

Macro International Inc.

June 13, 1997

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Total Focus Group Time: approximately 95 minutes

I. BACKGROUND AND INTRODUCTIONS (5- 10 minutes)

Objectives:

- Put participants at ease
- Explain purpose of discussion and focus group process

Moderator will introduce herself, welcome participants, and invite them to enjoy refreshments.

Purpose:

As you know from the phone call inviting you to participate, this discussion is part of a study being conducted by the Centers for Disease Control and Prevention. The purpose of the study is to learn more about what elder care providers think is important in terms of preventing disease and injury and promoting healthy behaviors among the elderly. We are also conducting similar discussion groups (both here in Atlanta and in rural areas) with family members and the elderly to also find out what they think is important in keeping elderly safe and healthy.

What you share with us today [tonight] will assist CDC in determining topics of interest and needs for the development of policies and guidelines regarding elder care. Because you are on the front lines of providing care for the elderly, your opinions are very important. We thank you in advance for coming out and sharing your opinions and ideas with us.

Procedures:

Before I ask you to introduce yourselves, I want to explain how this will work. I'm going to ask a series of questions to launch the discussion. Anyone can speak out; you don't need to wait for me to call on you. But please keep in mind that we have a lot to cover in our brief time together, so please don't be offended if I interrupt you to move on. It's important for us to hear from everyone, and to cover the topics in equal depth.

I also want to point out that there's no such thing as a wrong answer to these questions. We're interested in your opinions.

We are tape-recording this session, even though my colleague is taking notes as well. I hope that the tape recorder won't make anyone uncomfortable. We don't expect to get into any personal or controversial topics, but if we do, rest assured that we will not report on any comments by name. The recorder is purely for accuracy in our reporting. Please try to speak loudly and clearly, and one at a time.

Moderator will review consent form with participants.

Introductions:

Moderator will ask participants to introduce themselves, briefly describe the types of services they provide, and how long they have been involved in caring for the elderly.

II. HEALTH AND SAFETY INFORMATION (20 minutes)

One of the topics of interest to CDC is health and safety issues in elder care. Thus, we'd like to find out more about the kinds of health and safety information you have available to you, and what other kinds of materials might be helpful.

1. If you have a health and safety question, who do you usually call or where do you go to get more information?
 - colleagues
 - physician or nurse
 - handbooks or guidelines
 - published books
 - posters
 - journal articles
 - elderly or senior citizens organizations or others (e.g. Red Cross)
 - health department
 - professional organization
 - internet
 - local library

2. What situations or topics have you called someone about in the past, or tried to get more information about?
 - handwashing, cleaning, preventing the spread of diseases
 - injury prevention (prevention of falls, safetyproofing, etc)
 - CPR/ first aid
 - nutrition
 - disabilities (physical or mental)
 - mental health issues (depression, bereavement, mortality issues)

3. How often do you find you need health and safety information but it is not readily available?

4. What have you found to be the most useful sources of health and safety information?
5. Is there any health and safety information you wish you had, but don't? Think back to a recent question you had...
6. What format would you like this information in?

Probes:

- poster or factsheet
 - manual or handbook
 - video
 - pocket guide
7. What types of information are the most important—for example, health and safety information that was particularly surprising to you or the most helpful?
 8. Is there anything you do differently as part of your job as a result of health and safety information?

III. HEALTH AND SAFETY TRAINING (15 minutes)

1. Have you ever received any specific training or participated in any workshops related to elder care and/or safety?
2. Who or what organization provided these trainings?
3. What types of topics or issues were discussed in the training?

Probes:

- CPR/first aid
 - disease prevention (cleaning, handwashing, food preparation, etc.)
 - communication skills
 - nutrition
 - safety
4. Which information did you find most useful?
 5. What was missing from your training? Perhaps something you learned on the job, or figured out on your own?

For those who have not received any type of training...

6. If training courses or workshops were available, would you attend?
7. What kinds of health and safety information would you find most useful to learn about?
8. What about topics such as:
 - violence and abuse prevention
 - communication skills (how to convey health and safety messages to elderly and their family members)
 - mental health issues
 - nutrition
 - exercise and physical fitness
9. Where and when would it be most convenient to receive training?
10. What type of training format would you find most useful?
 - peer workshops
 - lectures
 - videos

IV. HEALTH AND SAFETY COMMUNICATION WITH ELDERLY (15 minutes)

1. What kinds of health and safety concerns do your clients and/or their families have?
2. Are these different from yours?
3. Do you discuss general health and safety issues with your clients? ***If applicable***, what about their families?
4. What health and safety issues are hard to explain or convey to your clients? Why?

Probes:

- level of information is too complex
- cultural issues
- gender issues
- age or generational issues
- fear (mortality, medical procedures)
- mental health issues

5. What materials are [or would be] helpful to share with your clients?
6. Are there materials you wish you had, to address a specific question or concern that comes up a lot? (e.g., first aid, nutrition, cleaning, etc.)

V. PUBLIC HEALTH ROLE (10-15 minutes)

As the US population ages, CDC has been receiving more and more requests for information on basic health issues and disease prevention procedures. Thus, CDC would like to adopt a more expanded role in providing elder care providers with the information they need to keep elderly safe and healthy. Let's spend the next few minutes talking about the potential role of health departments and CDC in encouraging and promoting health and safety.

1. Have you ever used the health department as a resource?

- to answer a specific question or give advice
- to provide brochures
- to make referrals

What was their response? Was it helpful?

2. For those of you who have not called the health department for information, why not?

- "just did not think about it"
- "did not think the health department could help me"
- "health department is not for health care questions"
- "health department is only for diseases or things like STDs or food poisoning"

3. What are some ways that the health department could be more helpful to you?

- hotline
- newsletter/updates on health and safety
- lending library for health and safety videos
- training workshops

VI. PREVENTION AND PUBLIC HEALTH SERVICES FOR ELDERLY (10 minutes)

1. When we talk about prevention we mean preventing diseases from occurring or finding out about a disease early enough to keep it from becoming too serious. If services to prevent diseases or illnesses could be offered to the elderly, which services would you consider most important or critical?

- dental check ups
- immunizations (flu shots, tetanus boosters, Hepatitis B vaccinations, etc.)
- vision and hearing screenings
- blood pressure checks
- diabetes screening
- nutrition
- smoking cessation

2. If you think about the clients you serve, what would be the best format or method of delivering these services to them?

- mobile vans
- local churches
- local health department and/or clinic
- local senior citizen's center
- a health fair through their living facility (e.g. their apartment complex, their assisted living facility, etc.)

3. Again, thinking about your clients, what would be the reasons why they *would not take* advantage of such services if they were made available?

Probes:

- costs
- transportation (if not very close by)
- access (physical impairment or disability issues)
- fear or distrust of medical care
- denial

4. As an elder care provider, would you be willing to assist your clients in either arranging or accessing such services (e.g. make an appointment for a screening, bring them to a local health fair, arrange a visit by a visiting health care provider, etc.)?

Why or why not?

Probes:

- too much of a burden (not within the scope of my job)
- my client would not be interested
- my client has a visiting nurse or private provider who attends to these needs
- finances (I would have to charge my client more and they could not afford it)
- not my role/not my job

VII. MATERIALS REVIEW AND CONCLUSION (10- 15 minutes)

In an effort ensure that health and safety information is as useful and relevant as possible, I would like you to spend the final 10 to 15 minutes of our discussion reviewing the materials I am passing around the table. Please think about the format (size, shape, color, print size, etc.) of these materials and tell me what you like and dislike most about what you are reading.

Those are all the questions I have. Does anyone have any other comments about any of the topics we've discussed--something you've thought of while we were talking about other things? Please feel free to call me at ---- if you think of something you'd like us to know about in the next few days.

Thanks again for taking the time to give us your opinions. Please remember to sign the participant list and receive your honorarium from me before you leave.

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