



**ICAN 2:
Investigating Caregivers'
Attitudes and Needs**

February 9, 2007

C o n d u c t e d o n B e h a l f o f :
The Alzheimer's Foundation of America (AFA)
and sponsored by Forest Pharmaceuticals, Inc.

Fieldwork:
January 9 to February 6, 2007

Project Managers:
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Introduction

ICAN 2: Investigating Caregivers' Attitudes and Needs was conducted by Harris Interactive on behalf of the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc. The purpose of this study was to assess any cultural differences in caregivers' attitudes and feelings towards caregiving including access to support groups, knowledge and education.

This report highlights findings among a nationally representative sample of caregivers who are involved in care and treatment decisions on behalf of a relative or friend with Alzheimer's disease. Primary topics covered in this survey include:

- Obstacles that may have delayed getting a diagnosis of Alzheimer's disease
- Attitudes towards and knowledge of Alzheimer's disease
- Access to support and advocacy groups
- Impact of caregiving responsibilities on the caregiver's own family and life

Survey Method and Sample

Harris Interactive surveyed a cross section of 655 U.S. caregivers who are involved in care and treatment decisions on behalf of a relative or friend with Alzheimer's disease during January 2007. Respondents were recruited from a sample purchased from an outside vendor and the Harris Interactive Online Panel (HPOL). All interviews were conducted via the telephone. Respondents recruited from the panel were invited to participate via email and provided a toll free number to participate. Interviews averaged 25 minutes in length.

A detailed survey methodology appears in Appendix A and the survey questionnaire in Appendix B of this report.

Findings

I. OBSTACLES TO DIAGNOSIS

- 1. On average, most patients in this study had been diagnosed with Alzheimer's disease roughly two years ago. In most cases, the length of time between first symptoms and a diagnosis can be measured in terms of years, not months.**
 - A typical patient experiences symptoms for almost three years (31.1 months) before receiving a diagnosis of Alzheimer's disease. African-American respondents are less likely to report such a gap between when their loved one experiences symptoms and diagnosis. On average African-American caregivers report their loved one experienced symptoms for approximately two years (24 months) prior to diagnosis compared to three years for Hispanic (35 months) and other race (36 months) caregivers.
- 2. Much of the time, caregivers put a good deal of responsibility on their lack of knowledge about the disease when asked to explain the main reasons for the delay in diagnosis. African Americans and Hispanics were significantly less likely to associate the symptoms with Alzheimer's disease.**
 - Most (63%) thought the symptoms of Alzheimer's disease were simply part of getting older, particularly among African Americans (70%) and Hispanics (67%) who were significantly more likely to associate the symptoms with old age than other race respondents (53%). Additionally, 59% stated that they did not know enough about the disease to recognize the symptoms, again significantly more so among African Americans (67%) and Hispanics (63%) than other races (49%).
 - Caregivers who did not know enough about the disease to recognize the symptoms were more likely to be younger (46.5-years-old) than caregivers who did know enough to recognize the disease (50.0- years-old), this is particularly true among African-American caregivers (48.9 vs. 50.3-year-old). Similarly, caregivers who consider Alzheimer's disease to be a normal part of the aging process are younger (45.9-years-old) compared to those who do not consider it a normal part of aging (49.0-years-old)
 - Caregivers who report not knowing enough about the disease to recognize the symptoms are more likely to have seen a delay in diagnosis for other reasons as well including having little access to a healthcare professional (17% vs. 10%; Among Hispanics 23% vs. 9%), having never been offered a memory screening (43% vs. 30%; Among other race 42% vs. 27%), fear that something could be wrong (40% vs. 25%; Among African Americans 45% vs. 30%) and fear of the responsibility (27% vs. 12%; significantly different across all racial groups).
- 3. Denial and resistance in visiting a doctor also accounted for the delay in diagnosis.**
 - Often the patient refused to visit a doctor (47%).

- Other times, it was denial on part of the caregiver. Just a third, 33%, did not want to face the possibility of something being wrong. Four in 10, 40%, of African-American caregivers did not want to face this possibility, compared to 30% of Hispanics and 29% of other races. Religious respondents were more likely to not want to face this possibility either (Religious 38% vs. Non-Religious 31%).
- While a fifth of all caregivers (20%) were fearful of the responsibility that an Alzheimer's disease diagnosis would place on them, significantly more so among African Americans (23%) and Hispanics (26%) than other race caregivers (14%).

4. Another reason for delay in diagnosis is disease stigma.

- One third (33%) say that the patient was concerned about the stigma of an Alzheimer's diagnosis.
- Some indicated that their own concern about a stigma was a reason for the delay (26%). African-American caregivers were significantly more concerned about stigma (36%) than Hispanic (22%) and other race (18%) caregivers. Males were more concerned than females about stigma associated with the disease (35% vs. 24%) as were religious respondents compared to non-religious respondents (33% vs. 22%).

5. Secondary reasons for delay in diagnosis included issues related to access and knowledge of the healthcare system.

- Almost four in 10 (38%) respondents stated that their loved one had not been offered a memory screening, while 24% did not understand their loved ones healthcare system.
- A small percentage of respondents stated that their loved one had no access to healthcare (14%, African-American Males 24% vs. African-American Females 13%) or could not afford coverage (15%).
- While 13% were concerned that an Alzheimer's disease diagnosis would result in disqualification for long-term care insurance.

6. Delay in diagnosis of Alzheimer's disease was not blamed on ethnic or language barriers, regardless of ethnic background.

- Only 7% of respondents reported not being able to find a healthcare provider that shared their ethnicity; males were significantly more likely to run into this problem (Males 15% vs. Females 5%). African-American and Hispanic respondents are slightly more likely to report this as a problem but ratings were still low, 8% and 10% respectively compared to 3% for other race caregivers. African-American males were more likely to report this as a problem (African-American Males 27% vs. African-American Females 4%).
- Less than 1% of caregivers stated not being able to find information in their primary language or a healthcare professional who spoke their primary language as a barrier to diagnosis.

II. ALZHEIMER'S DISEASE ATTITUDES

- 1. Respondents agree that there is an emotional impact of caring for a loved one with Alzheimer's disease (no significant differences among ethnic subgroups). However, females are significantly greater than males to agree that there is an emotional impact.**
 - Given this powerful emotional impact, it is not surprising that the vast majority of caregivers indicate that Alzheimer's disease is life-changing for the family of someone who is diagnosed (97%) and that having a loved one with Alzheimer's disease can be quite stressful (97%).
 - Additionally, many feel overwhelmed (73%, Unprepared 78% vs. Prepared 68%) and helpless (50%, Females 52% vs. Males 38%, Religious 57% vs. Non-Religious 46%, Unprepared 55% vs. Prepared 41%, African-American Religious 60% vs. African-American Non-Religious 45%) when caring for their loved one.
- 2. Even though the impact of Alzheimer's disease can be life-changing for the family, many respondents accept the disease as a normal part of the aging process.**
 - Three in 10 (31%) of caregivers consider Alzheimer's disease to be a normal part of the aging process. African Americans (37%) and Hispanics (33%) are significantly more likely to believe this statement compared to other race (23%) caregivers. Caregivers, who report not knowing enough about the disease to recognize the symptoms, are more likely to consider Alzheimer's disease as a normal part of the aging process (34% vs. 23%).
 - Half of caregivers believe most people will develop some form of Alzheimer's disease as they get older; this is particularly true among African-American (56%) and Hispanic (62%) caregivers compared to other race (44%) caregivers. Not surprisingly, caregivers who believe Alzheimer's disease is a normal part of the aging process are also more likely to believe most people will develop some form of Alzheimer's disease as they get older (81% vs. 41%; consistent gap across racial groups). African-American and Hispanic caregivers who do not believe Alzheimer's disease is part of the normal aging process still believe most people will develop some form of the disease as they get older (46% and 51% respectively vs. 33% among other race caregivers).
 - Caregivers who consider Alzheimer's disease a normal part of the aging process are more likely to consider the disease to be a mental illness that should be treated by a psychiatrist (34% vs. 21%, this is consistent across racial groups).
 - African Americans (33%) and Hispanics (26%) are also more likely to recognize that they are at a higher risk for the disease, compared to 12% of other race givers who recognize the greater risk among African American and Hispanic populations.
- 3. Caregivers have practical day-to-day concerns regarding Alzheimer's disease.**
 - There are more practical, day-to-day concerns, such as the cost of caring for a person with Alzheimer's disease (78%, Unprepared 82% vs. Prepared 74%) and the concern about their ability to provide care as the disease progresses (70%).

- Respondents who were unprepared for their loved one to get Alzheimer's disease were significantly more likely to agree than those who were prepared about their ability to continue to provide care as the disease progresses (Unprepared 75% vs. Prepared 63%),

III. CAREGIVER NEEDS

1. **While caring for a loved one with this condition will be emotionally taxing no matter what, caregivers indicate that extra help in certain areas could ease the burden. When asked to indicate the areas in which they could have used more help, respondents mention a diverse range of types of assistance. Generally, African Americans report that more support could have been used.**
- At the time of diagnosis, level of preparedness varied by respondent. Respondents were slightly more likely to say they felt somewhat/very unprepared (48%) than they were to indicate feeling somewhat/very prepared (44%). Other race respondents were more likely to feel prepared (49%) than African-American (40%) or Hispanic (42%) caregivers. Caregivers who report not knowing enough about the disease to recognize the symptoms were more likely to feel unprepared compared to their counterparts (57% vs. 32%), this is consistent across all ethnic groups.
- Caregivers indicated that they could have used more support in the form of knowledge and direction from healthcare professionals. At the time of diagnosis, they wish they had more information about treatment options (75%) and had received more general information about Alzheimer's disease (75%), significantly higher among African Americans at 83% and religious respondents (80%). Support from experienced caregivers could have been higher (71%); especially among religious respondents (76% vs. Non-Religious 69%). Support from healthcare professionals (68%), again higher among African Americans (76%, African-American Females 78% vs. African-American Males 66%). In addition, local resources would also have been useful (64%); also among religious respondents (71% vs. Non-Religious 61%).
- Caregivers (70%), females (72% vs. Males 62%), and religious respondents (78% vs. Non-Religious 66%) wished they had more general emotional support and support from friends and family (68%). Financial (56%) and legal (45%) support would also have been of assistance, among religious respondents as well (62% vs. Non-Religious 53%), (59% vs. Non-Religious 39%). However, it seems respondents received enough support from their employers (32%), although religious respondents felt they could have used more (41% vs. Non-Religious 27%). Overall, African Americans were more likely to report that they could have used more information in these areas.
- Many respondents (67%) wished they had a healthcare professional who understood them and their family (again significantly higher among African Americans, 74%).
- Generally speaking, respondents were happy with the support they received from their religious leaders, just over a third (35%) wishing they had more. Religious respondents reported a higher level of want with help from religious leaders when compared to non-religious respondents (51% vs.

27%). However, African Americans were less pleased with 46% saying they could have used more support, compared to 36% Hispanic and 23% of other race caregivers.

- Caregivers who were unable to recognize the symptoms of Alzheimer's disease said they could have used more information in several areas. African Americans in particular who were unable to recognize the symptoms felt they could have used more financial support (71%), support/flexibility from their employer (46%), and general information about Alzheimer disease (88%).

- Unprepared caregivers report having increased stress or anxiety levels than prepared caregivers (67% vs. 58%).

2. Taking care of someone with Alzheimer's disease is often very disruptive to the caregiver's life. However, there is a silver lining in that many caregivers feel that they are more compassionate now and it has brought them closer to their family.

- Caregivers report not having as much time for themselves (73%), are not able to get out as much as before (67%) and are more anxious, stressed or burnt-out (63%). Those that take care of a parent are more likely to feel abandoned by family (41%) than those that take care of a spouse or another person. Religious respondents are less likely to have become more anxious or stressed out (58% vs. Non-Religious 65%). Females in general and African-American females are more likely to feel that they are abandoned by their family (33% vs. Males 19%, 34% vs. African-American Males 11%).

- However, caregivers do feel more compassionate (80%). Interestingly, African Americans (85%), Hispanics (81%), feel more compassionate than other race caregivers (73%). This also applies to religious respondents (87% vs. Non-Religious 76%). And, caregivers have developed close ties with their family (69%), particularly among African-American (70%) and Hispanic (75%) caregivers relative to other race (64%) caregivers. This also applies to Males in general (76% vs. Females 67%), African-American Males (82% vs. African-American Females 68%), and Religious respondents (75% vs. Non-Religious 66%).

- There has also been an increase in religiousness for some (37%), more so among African Americans (48%), compared to Hispanics (35%) and other race (26%) respondents. Some also report becoming advocates for the cause (46%), perhaps not surprisingly more so among people who use support and advocacy groups. Religious respondents report becoming more religious through this experience (49% vs. Non-Religious 30%) and becoming an advocate for the cause (55% vs. Non-Religious 42%).

3. Most caregivers take some time away for themselves. Among those that don't, they either feel the full responsibility lies on them or they can't find or afford coverage.

- Just over three-quarters of respondents (76%) say they take time off from caregiving to relax when they are feeling overwhelmed. African-American Males and religious respondents are more likely to take time off to relax than African-American females or non-religious respondents, respectively (African-American Males 89% vs. African-American Females 76%, Religious 82% vs. Non-Religious 73%).

- Typically, another family member or friend steps in during their absence, 76%, particularly among African-American (82%) compared to Hispanic (77%) and other race caregivers (69%). In the case of the African-American subgroup, Males (13%) are more likely than females (5%) to have a neighbor step in to take care of their loved one, but females (14%) are more likely than males (3%) to have a day care facility takeover. Religious respondents are more likely than non-religious respondents to have other family members or friends take care of their loved one (Religious 82% vs. Non-Religious 73%).
- Prepared caregivers are more likely than unprepared caregivers to hire a nurse or home health aid to help care for their loved one (27% vs. 19%). Prepared African-American caregivers are more likely to hire a home health aid than unprepared African-American caregivers (33% vs. 22%).
- Among those that don't take any time off, they feel responsible (43%), can't afford help (42%), or no one else is available to help (39%).

IV. ACCESS TO SUPPORT AND ADVOCACY GROUPS

- 1. Most caregivers agree that support is needed when caring for someone with Alzheimer's disease. However, many feel that they do not have the support they need from their family or friends. African-American females are significantly more likely to agree that family support is needed when caring for a loved one with Alzheimer's disease, while both females in general and African-American females agree they wish they had more support than their Male counterparts. There are also significant differences among religious respondents.**
 - A majority of caregivers agree that the support of the entire family is needed when caring for a loved one with Alzheimer's disease (92%, Females 93% vs. Males 88%, Religious 96% vs. Non-Religious 90%, Hispanic Unprepared 98% vs. Hispanic Prepared 90%). Interestingly, almost three-quarters (74%, Females 76% vs. Males 66%, African-American Females 81% vs. African-American Males 68%, Religious 80% vs. Non-Religious 71%) wish they had more support from their families or friends, with 61% (Religious 70% vs. Non-Religious 57%, African-American Religious 74% vs. African-American Non-Religious 55%) reporting satisfaction in the support services available.
- 2. Generally, caregivers are satisfied with their ability to find support resources in their primary language. Male respondents are more likely than females to be embarrassed to seek outside support for their loved one with Alzheimer's disease.**
 - Most have no trouble finding support resources in their primary language (82%).
 - Males are more likely to be embarrassed to seek outside support services for their loved one with Alzheimer's disease (Males 11% vs. Females 7%, African-American Males 16% vs. African-American Females 5%).
- 3. Many caregivers have access to support or advocacy groups. Typically, groups are hosted by a hospital or clinic.**

- Many caregivers report having access to Alzheimer's disease support groups (40%) or advocacy organizations (40%), with caregivers from other races being significantly more likely to agree to both, 47% and 49% respectively. Religious respondents (47%) are significantly more likely to have access to an Alzheimer's disease support groups for caregivers than non-religious respondents (36%). Religious respondents are also significantly more likely to have access to Alzheimer's disease advocacy organizations (Religious 46% vs. Non-Religious 37%). Caregivers who were unable to recognize the signs of Alzheimer's disease were less likely to see they have access to Alzheimer's disease/caregiving advocacy organization (37% vs. 46%).
 - Groups are most often hosted by a hospital or clinic, (64%, Religious 71% vs. Non-Religious 60%), followed by a community center (46%), and a house of worship (33%, Religious 50% vs. Non-Religious 22%).
 - Unprepared caregivers who have access to support groups when compared to prepared caregivers report that most are hosted by hospitals or clinics (71% vs. 57%).
 - Respondents are divided when asked if these groups are appropriate for caregivers specific to their religious or ethnic background. 44% feel the groups are appropriate and 38% said no. African Americans (47%) were more likely than Hispanics (38%) to feel the groups were appropriate, while some were unsure 15% and 24% respectively. Respondents classified as religious were also more likely to say yes (Religious 53% vs. Non-Religious 37%).
- 4. African-American and Hispanic caregivers tend to use support and advocacy groups more frequently than caregivers of other races.**
- Among those with access to support groups, only 39% of respondents currently participate, with another 26% saying they have participated in the past. Religious respondents are more likely to be using support groups (Religious 50% vs. Non-Religious 32%, Other Race Religious 45% vs. Other Race Non-Religious 32%). African Americans (47%) and Hispanics (50%) are significantly more likely to currently use a support group compared to other race (29%) caregivers.
 - Among those with access who have not participated, many feel they do not have time (49%), already have enough knowledge on the matter (47%) or their family (45%) and friends (40%) provide enough support. African-American caregivers are more likely to cite that they do not have any groups in their immediate area (32%). Religious respondents who have not participated in a support group are significantly greater than non-religious respondents to cite that support group values are not sensitive to their religious background (Religious 12% vs. Non-Religious 1%). Non-religious respondents are significantly more likely to say they feel they have to go it alone in caring for their loved one (Non-Religious 19% vs. Religious 8%). Unprepared caregivers are significantly more likely than their counterparts to have no time to participate in support groups (59% vs. 36%). Not surprisingly, prepared caregivers feel they are knowledgeable enough already (56% vs. Unprepared Caregivers 39%).

- About four in 10, 41%, are currently using advocacy groups, with another 23% having used them in the past. Again, African-American (47%) and Hispanic (57%) caregivers tend to take advantage of groups more often than caregivers from another race (30%).

V. PERSONAL SUPPORT SYSTEM OF CAREGIVERS

1. **Overall, caregivers tend to rely on physicians, friends and family for support, with African-American caregivers significantly more likely to rely on several areas of support. Religion seems to play a role in who seeks support from multiple sources.**
 - Caregivers tend to use the following sources of information for Alzheimer's disease most frequently: their loved one's doctor (80%), their doctor (67%) and information on websites (73%). African-American males are more likely than African-American females to use their doctor as a source of information (82% vs. 65%) and use information on websites (80% vs. 67%). African-American females are more likely to use their loved one's doctor as a source of information (82% vs. 70%). Religious respondents are more likely than non-religious respondents to use: their loved one's doctor (84% vs. 78%), information on Web sites (78% vs. 71%), and medical journal articles (73% vs. 64%).
 - In general, caregivers are most likely to turn to physicians (64%), friends (62%), siblings (59%), religious leaders (59%) and support groups (53%) for support when they are feeling overwhelmed. Females are significantly more likely than males to turn to siblings (61% vs. 50%), children (51% vs. 30%), friends (65% vs. 49%), and religious/spiritual leaders (61% vs. 50%) for support. Males are significantly more likely to seek out therapists for support than females (47% vs. 36%). African Americans are significantly more likely to turn to friends (66%), religious leaders (74%) and support groups (61%) than Hispanic and other caregivers. Religious respondents are significantly more likely than non-religious respondents to get support from siblings (64% vs. 56%), children (54% vs. 44%), friends (75% vs. 55%), co-workers (31% vs. 20%), religious/spiritual leaders (100% vs. 38%), therapist (45% vs. 34%), and support group members and/or other Alzheimer's disease caregivers (67% vs. 46%).
 - Overall, unprepared caregivers are more likely to seek support from religious/spiritual leaders than prepared caregivers (61% vs. 55%). Unprepared Hispanics are more likely than prepared Hispanics to turn to friends (65% vs. 44%), and religious/spiritual leaders (Unprepared Hispanics 62% vs. Prepared Hispanics 43%).
2. **Religion tends to play an important role in the lives of caregivers, from their seeking support to making healthcare decisions based on spiritual beliefs. Not surprisingly, respondents who are religious are more likely to turn to religious leaders for support and let their religion influence their healthcare decisions than non-religious respondents.**
 - Respondents are likely to turn to their religious leaders for support (54%, Religious 73% vs. Non-Religious 31%) with their spiritual beliefs having a significant impact on their healthcare decisions (84%, Religious 100% vs. Non-Religious 63%).

- Caregivers who are less likely to recognize the symptoms of Alzheimer's disease are more likely to turn to their religious leaders for support (64% vs. 54%).

VI. LIVING SITUATION AND NURSING HOME POSSIBILITY

1. **A majority of caregivers report that their loved ones are not living in a nursing or assisted living facility. Additionally, many will not consider this as an option in the future and are not hiring outside help. However, there is a fairly large minority that will at least consider a facility as an option.**
- Many caregivers report that their loved one lives either with them (47%) or another family member (11%). About a one-fifth are currently living in a nursing (17%) or assisted living facility (5%), with 15% living in their own homes with the assistance of aids.
- A majority of caregivers (68%) have not considered putting their loved one in a nursing facility. However, a large minority, 30% have considered this option of care. Furthermore, most (56%) do not anticipate considering a nursing home or assisted living facility in the future, with 24% thinking it is a possibility. Other race caregivers (32%) are significantly more likely to think placing their loved one in a facility is an option in the future compared to African-American (19%) and Hispanic (21%) caregivers.
- Caregivers who will not place their loved one in a facility feel that it is their responsibility to take care of their loved one (85%) or they say they would feel guilty (60%). Other reasons include "can not afford it" (27%), "my family would look down on me for doing so" (19%) and "the nursing home/assisted living facility has a majority of staff/residents who are a different ethnicity/culture from my loved one" (14%).
- Caregivers who would consider a nursing facility in the future state that when their loved ones physical safety is in danger it would be a good time for a facilities assistance (83%). When behavior problems arise (60%) and their loved one no longer recognizes them (51%) are also points when a facility would come into play.
- Interestingly, most caregivers with loved ones not in a facility have also not hired outside help (64%). Male caregivers are more likely to have hired help than females, 47% compared to 32% (Other Race Males 47% vs. Other Race Females 33%, African-American Males 50% vs. African-American Females 32%). Caregivers who are less likely to recognize the symptoms of Alzheimer's disease are more likely than their counterparts to have hired outside help (40% vs. 31%); particularly among other race caregivers (45%)

VII. TREATMENT HISTORY

1. **The physician who is primarily responsible for treating the loved one with Alzheimer's disease tends to be a generalist. Respondents tend to be have been highly involved the decision of which healthcare professional to use.**

- A general/family practitioner is the primary healthcare professional for just over half of respondents (57%) with a majority of caregivers stating that they were somewhat/very involved with the selection of this healthcare professional (71%). Females are more likely than males to be very involved in choosing a healthcare professional (54% vs. Males 41%); the same applies to females of other racial background (54% vs. Other Race Males 39%).
 - Multiple criteria were used to select the healthcare professional treating their loved one. Distance to their home (46%), referral from another healthcare professional (45%) and on insurance plan (37%) were the most commonly mentioned. Also, males look for healthcare professionals to be a leader in treating Alzheimer's as leading criteria (42% vs. Females 28%, Other Race Males 44% vs. Other Race Females 26%). Other race males and religious respondents look for a referral from another healthcare provider (56% vs. Other Race Females 34%, Religious 51% vs. Non-Religious 42%).
 - African-American and Hispanic caregivers are less likely to mention ethnic background as selection criteria for their loved one's physician (13% and 12% respectively).
- 2. Caregivers have heard the name of one or more medications that are available, and in most cases their loved one is currently taking a prescription medication for Alzheimer's disease.**
- Of the treatments studied, caregivers are most likely to have heard of Aricept/donepezil (77%) and females more likely than males (79% vs. 67%), also among African-American females (76% vs. African-American Males 64%). Over two-thirds have heard of antidepressants in general (69%) and religious respondents are more likely to have heard of antidepressants (76% vs. Non-Religious 65%). A minority have heard of Razadyne/Reminyl/galantamine (42%), Namenda/memantine (42%), antipsychotics (35%) or Exelon/rivastigmine (31%). Religious respondents were more likely to have heard of Razadyne/Reminyl/galantamine (50% vs. Non-Religious 38%) and Exelon/rivastigmine (37% vs. Non-Religious 29%).
 - Their loved ones have typically been on prescription medication for close to four years. Loved ones are most likely to be currently taking Aricept/donepezil (53%) followed by antidepressants (35%). A quarter or fewer are currently taking Namenda/memantine (24%), antipsychotics (15%), Razadyne/Reminyl/galantamine (12%) or Exelon/rivastigmine (11%). Males and religious respondents are more likely to report that their loved one is taking Razadyne/Reminyl/galantamine (19% vs. Females 11%, Religious 17% vs. Non-Religious 10%). African-American males are more likely than their counterparts to report that their loved one is on antidepressants (43% vs. African-American Females 27%).
- 3. Most caregivers are not currently aware of the opportunity for combination therapy.**
- A majority (67%) were not aware of the opportunity for combination therapy. African-American caregivers (26%) are significantly less likely than Hispanic (32%) and other race (38%) caregivers to be aware.

- Caregivers who were unable to recognize the symptoms of Alzheimer's disease are less likely to be aware of combination therapy (71% are unaware vs. 59%); this is particularly true among African Americans (76%) and other race caregivers (64%).

IX. CAREGIVER AND PATIENT PROFILES

1. Alzheimer's caregivers tend to be middle-aged and caring for a family member who typically lives in their household. Despite over sampling Hispanics, all respondents were fluent in English.

- Average age is 48, with a majority being female (80%).
 - Most care for a parent who has been diagnosed with Alzheimer's (49%) followed by those who care for a grandparent (20%), other family member (14%), spouse (11%) or friend (6%).
 - Large minority of the patients are living with their caregivers (47%), with 17% living in a nursing facility.
 - All respondents were fluent in English with 38% reporting they are also fluent in Spanish – no respondents took the survey in Spanish.
 - Majority of respondents state that they are extremely or very religious (55%), with most being Christian (84%), mainly Baptist (34%) and Catholic (25%). Females report being more religious than males (60% vs. Males 38%, Other Race Females 50% vs. Other Race Males 27%, African-American Females 71% vs. African-American Males 57%).
 - A large minority of respondents are from the South (47%) and live in suburban areas (43%).
 - East (20%)
 - Midwest (20%)
 - West (13%)
 - Tendency to be married (47%) and employed full-time (36%).
 - Additionally, tend to be high school graduates (24%) or have some college (30%).
 - Tend to be lower income, with 51% having a household income of less than \$35,000.
- ### 2. These caregivers are most likely to care for a female patient who is in her late 70's.
- Average age is 79.
 - Most are female (70%).

Appendix A: Methodology

Harris Interactive conducted *ICAN 2: Investigating Caregivers' Attitudes and Needs* on behalf of the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc.

About the Survey

The *ICAN 2: Investigating Caregivers' Attitudes and Needs* survey examined the cultural differences in caregivers' attitudes and feelings towards care giving including access to support groups, knowledge and education. The survey is based on interviews with 655 U.S. adults (aged 18+) who are caregivers – currently caring for a loved one with Alzheimer's disease – conducted by telephone within the United States by Harris Interactive from January 9 to February 6, 2007, for the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc. Data from the survey were not weighted.

Sample

Potential respondents were drawn from an outside sample house targeting households with at least one member having Alzheimer's disease. Additionally, individuals registered with Harris Interactive's online database were also recruited. Email invitations were sent to panel members inviting them to participate in the survey by dialing into a toll free number. All other respondents were called directly by the interviewers.

Interviewing Procedures

Interviews were conducted via CATI (Computer Assisted Telephone Interviewing) utilizing our Orem, Utah telephone center with 120 stations. All telephone research is monitored by our Quality Control Team. Quality and consistency is ensured by adhering to previously implemented ISO processes and procedures with all in-house Interviewers and Supervisors completing our Quality Training. All outsourced partners are audited to review their capabilities and also receive our Quality Training.

The CATI software has a built-in sample management tool which enables the system to randomly issue sample to the interviewers and appropriately disposition each record. This ensures each number is dialed a certain number of times before being considered exhausted.

Editing and Cleaning the Data

The data-processing staff performs machine edits and additional cleaning for the entire data set. The edit programs act as a verification of the skip instructions and other data checks that are built into the CATI-based interviewing programs. The edit programs identify errors that are subsequently resolved by programming personnel (and when appropriate, project staff), who inspect the original file and make appropriate corrections. Complete records are kept of all such procedures.

All data are tabulated, checked for internal consistency and processed by computer. A series of computer-generated tables is then produced for each of the key sample groups showing the results of each survey question, both by the total number of respondents and by important subgroups.

In theory, with samples of this size, one could say with 95% certainty that the overall results have a sampling error of plus or minus four percentage points. Sampling error for the sub-samples of caregivers is higher and varies.

**Appendix B:
Questionnaire**

Harris Interactive

J29688

Alzheimer's Disease Minority Caregiver Research
Draft Questionnaire 1/02/07

Thank you for agreeing to participate in this survey. We are conducting an important study about issues related to consumer health care.

Your responses and your identity will, of course, be kept strictly confidential. Only group findings will be reported.

If you would like to complete this survey in Spanish, please tell me now.

SCREENER

S1. (102) ***Interviewer: Record Gender.***

Male xx-1
Female -2

S2. (104) In what year were you born ?

Year born: |____|____|____|

[TERMINATE IF UNDER 18]

S3. (110) In which country do you currently reside? ***Do not read list.***

[DROP-DOWN MENU]

[TERMINATE IF NOT FROM UNITED STATES]

S4. (330) Do you have a family member or friend who has been diagnosed with Alzheimer's disease?

Yes xx-1
No -2
Decline to answer (vol.) -3

[TERMINATE IF NO OR DECLINE TO ANSWER]

S5. (335) Is this person your...? ***Read list. Select one answer only.***

- | | | |
|----------------------|--------------------------|------|
| Spouse..... | <input type="checkbox"/> | xx-1 |
| Parent | <input type="checkbox"/> | -2 |
| Grand parent | <input type="checkbox"/> | -3 |
| Sibling | <input type="checkbox"/> | -4 |
| Child..... | <input type="checkbox"/> | -5 |
| Other relative | <input type="checkbox"/> | -6 |
| Friend..... | <input type="checkbox"/> | -7 |
| Other | <input type="checkbox"/> | -8 |

S6. (340) How involved are you in the care of the person you know with Alzheimer's disease?

- | | | |
|---|--------------------------|------|
| Very unininvolved..... | <input type="checkbox"/> | xx-1 |
| Somewhat unininvolved..... | <input type="checkbox"/> | -2 |
| Neither involved nor unininvolved | <input type="checkbox"/> | -3 |
| Somewhat involved | <input type="checkbox"/> | -4 |
| Very involved | <input type="checkbox"/> | -5 |

[TERMINATE UNLESS SOMEWHAT/VERY INVOLVED]

S7. (345) How involved are you in making decisions about Alzheimer's treatments for the person you know with Alzheimer's disease?

- | | | |
|---|--------------------------|------|
| Very unininvolved..... | <input type="checkbox"/> | xx-1 |
| Somewhat unininvolved..... | <input type="checkbox"/> | -2 |
| Neither involved nor unininvolved | <input type="checkbox"/> | -3 |
| Somewhat involved | <input type="checkbox"/> | -4 |
| Very involved | <input type="checkbox"/> | -5 |

S8a. (236) Are you of Hispanic origin, such as Latin American, Mexican, Puerto Rican, or Cuban?

- | | | |
|---------------------------------|--------------------------|------|
| Yes, of Hispanic origin | <input type="checkbox"/> | xx-1 |
| No, not of Hispanic origin..... | <input type="checkbox"/> | -2 |
| Decline to answer..... | <input type="checkbox"/> | -3 |

ASK Q.S8b IF OF HISPANIC ORIGIN. ALL OTHERS SKIP TO Q.S9.

S8b. (xxx) Are you of ...?

Latin American origin	<input type="checkbox"/>	xx-1
Mexican origin	<input type="checkbox"/>	-2
Puerto Rican origin.....	<input type="checkbox"/>	-3
Cuban origin	<input type="checkbox"/>	-4
Decline to answer.....	<input type="checkbox"/>	-5

S9. (238) Do you consider yourself...?

White	<input type="checkbox"/>	xx-1
Black	<input type="checkbox"/>	-2
African American	<input type="checkbox"/>	-3
Asian or Pacific Islander	<input type="checkbox"/>	-4
Native American or Alaskan native	<input type="checkbox"/>	-5
Mixed racial background	<input type="checkbox"/>	-6
Other race (specify: _____)	<input type="checkbox"/>	-7
Decline to answer	<input type="checkbox"/>	-8

[TERMINATE IF DECLINE TO ANSWER]

S10. (xxx) How fluent are you in the following languages?

- 1 - Not at all fluent**
- 2 - Somewhat fluent**
- 3 - Fluent**
- 4 - Very fluent**
- 5 - Extremely fluent**

English	_____
Spanish	_____

S11. (186) What language do you prefer to use in everyday life?

English	<input type="checkbox"/>	xx-1
Spanish	<input type="checkbox"/>	-2
Other	<input type="checkbox"/>	-3

Summary of Qualification Criteria for Alzheimer's Caregivers

- Must live in the U.S.

- Must be age 18 or older
- Must have a friend or family member who has been diagnosed with Alzheimer's disease
- Must be somewhat or very involved in the person's care

ALZHEIMER'S DISEASE ATTITUDES AND KNOWLEDGE

1. (400) I would now like to read you a list of statements that may describe your feelings about Alzheimer's disease. For each statement please tell me how much you agree or disagree with each statement.
Interviewer: Read scale below and repeat as necessary for each statement.

- 1 - Strongly disagree
- 2 - Somewhat disagree
- 3 - Neither agree nor disagree
- 4 - Somewhat agree
- 5 - Strongly agree

[RANDOMIZE]

- a. Alzheimer's disease is life changing for the family of someone who is diagnosed.....
- b. Having a loved one with Alzheimer's disease can be quite stressful.....
- c. I am concerned about my ability to continue to provide care as the disease progresses.....
- d. I feel overwhelmed when caring for my loved one with Alzheimer's disease
- e. I am concerned about the cost of caring for my loved one's Alzheimer's disease.....
- f. I feel helpless when caring for my loved one with Alzheimer's disease
- g. I wish my family and friends would assist more with care giving.
- h. I am satisfied with the support services available to me as a caregiver.....
- i. It takes the support of the entire family to care for someone with Alzheimer's disease.....
- j. Alzheimer's disease is a normal part of the aging process.....
- k. Most people will develop some form of Alzheimer's disease as they get older
- l. People with Alzheimer's disease are not sane.....
- m. I am able to find helpful support and resources in my primary language **[Ask only if primary language is not English]**
- n. Alzheimer's disease is a mental illness that should be treated by a psychiatrist
- o. There is a higher risk factor for Alzheimer's disease among African-Americans and Hispanics than Caucasians
- p. I am too embarrassed to bring up the topic of Alzheimer's disease with my doctor.....
- q. I am too embarrassed seek outside support services for my loved one's Alzheimer's disease.....

SUPPORT FOR CAREGIVERS

- 2a. (530) When you are feeling overwhelmed with the responsibilities associated with being a caregiver, who do you turn to for support? ***Read list. Select all that apply.***

Physicians/health care professionals	<input type="checkbox"/>	xx-1
Spouse.....	<input type="checkbox"/>	-2
Siblings	<input type="checkbox"/>	-3
Children.....	<input type="checkbox"/>	-4
Friends.....	<input type="checkbox"/>	-5
Co-workers	<input type="checkbox"/>	-6
Religious leaders or spiritual leaders (i.e. priest, rabbi, imam, etc)	<input type="checkbox"/>	-7
Therapist.....	<input type="checkbox"/>	-8
Support group members and/or other Alzheimer's caregivers.....	<input type="checkbox"/>	-9
Other person/people	<input type="checkbox"/>	-10
I do not turn to anyone.....	<input type="checkbox"/>	-11

(ASK Q.2b IF USE RELIGIOUS/SPIRITUAL SUPPORT SYSTEM IN Q.2a.)

- 2b. (xxx) How often do you turn to religious/spiritual leader for support? ***Read list.***

Rarely.....	<input type="checkbox"/>	xx-1
Sometimes.....	<input type="checkbox"/>	-2
Frequently	<input type="checkbox"/>	-3
Always.....	<input type="checkbox"/>	-4

- 3a. (xxx) When making decisions about the care that is provided to your loved one, what type of impact do your religious/spiritual beliefs have on your health care decisions you make on behalf of your loved one with Alzheimer's? ***Read list.***

No impact.....	<input type="checkbox"/>	xx-1
Moderate impact.....	<input type="checkbox"/>	-2
Significant impact	<input type="checkbox"/>	-3

(ASK Q.3b IF RELIGION HAS IMPACT ON DECISION MAKING IN Q.3a.)

- 3b. (465) How do your religious/spiritual beliefs impact your health care decision making? ***Probe until unproductive.***
-
-
-

4a. (xxx) When you are feeling overwhelmed do you ever take some time off from care giving to relax?

Yes xx-1
 No -2

(ASK Q.4b OF THOSE WHO DO NOT TAKE TIME AWAY OR OFF IN Q.4a.)

4b. (xxx) Why do you not take time away or off from care giving to relax? **Read list.**

No one else is able to take care of my loved one xx-1
 No one else can take care of my loved one as well as I can -2
 I do not trust other people to take care of my loved one -3
 I do not need a break -4
 I feel I need to take on full responsibility -5
 I do not feel comfortable asking someone else to help -6
 I cannot afford outside help -7
 I cannot find a health care provider who speaks my language or understands
my culture -8
 Other -9

(ASK Q.4c OF THOSE WHO TAKE TIME AWAY OR OFF IN Q.4a.)

4c. (xxx) When you take time off to relax from care giving, who takes care of your loved one? **Read list.**

I hire a nurse or home health aid to help care for my loved one xx-1
 Other family members or friends take care of my loved one – separate friends/family -2
 My loved one is able to take care of himself/herself for that period of time -3
 Home health aid -4
 Neighbor -5
 Day care facilities -6
 I leave my loved one for brief overnight stays at a long term care or assisted living
facility -7
 Other -8

5. (420) Do you have on-going access to...? **Read list. Select all that apply.**

Alzheimer's disease support groups for caregivers xx-1
 Alzheimer's disease/care giving advocacy organizations (such as the Alzheimer's
Foundation of America, Alzheimer's Association/caregiver organization) -2

Neither of these -3
Not sure (vol.) -4

(ASK Q.6 IF ENGLISH IS NOT PRIMARY LANGUAGE)

6. (xxx) Are these support groups offered in your primary language?

- Yes xx-1
No -2
Not sure -3

(ASK Q.7 IF BLACK OR HISPANIC RESPONDENT)

7. (xxx) Are these support groups appropriate for caregivers specific to your religious or ethnic background, for example the Hispanic/African American Caregiver Group ?

- Yes xx-1
No -2
Not sure -3

(ASK Q.8 OF THOSE WHO HAVE ACCESS TO SUPPORT GROUPS)

8. (425) You indicated that your community has Alzheimer's disease support groups for caregivers. Have you ever used these support groups to help you find information and resources about Alzheimer's and caring for people with Alzheimer's?

- Yes, I use support groups currently xx-1
I used to use support groups but not currently -2
I have never used a support group -3

(ASK Q.9 OF THOSE WHO HAVE ACCESS TO SUPPORT GROUPS BUT DO NOT USE THEM CURRENTLY)

9. (427) Why have you not participated/are you no longer participating in a support group? **Read list. Please select all that apply.**

[RANDOMIZE]

- None in my immediate area xx-1
- I didn't feel like I fit in -2
- I feel they don't understand my culture/not understanding my cultural background -3
- Their values are not sensitive to my religious background..... -4
- My care giving roles/responsibilities are different from other support group members -5
- I am not comfortable sharing feelings..... -6
- I have no time to participate..... -7
- I have no desire to participate..... -8
- I feel knowledgeable enough already..... -9
- I feel that I have to do this alone..... -10
- No support group in my area that uses my primary language (**ASK ONLY IF ENGLISH IS NOT PRIMARY LANGUAGE**)..... -11
- I feel that my family looks down on support groups..... -12
- My family is enough support so there is no need to go to outside source for help -13
- My friends are enough support so there is no need to go to outside source for help -14
- I don't think I would feel comfortable with the other people in the support group -15
- I don't think I would have much in common with the other people in the support group -16
- In general, the groups don't understand my needs/primary goals, lifestyle -17
- Other -18

(ASK Q.10 OF THOSE WHO HAVE ACCESS TO ADVOCACY ORGANIZATIONS)

10. (430) You indicated that you have access to Alzheimer's disease advocacy organizations in your community. Have you ever used these advocacy organizations to help you find information, counseling and resources about Alzheimer's and caring for people with Alzheimer's?

- Yes, I use advocacy organizations currently xx-1
- I used to use advocacy organizations..... -2
- I have never used advocacy organizations -3

11. (xxx) Which sources of information did you use to learn about Alzheimer's disease. **Select all that apply.**

[RANDOMIZE]

- Your personal doctor xx-1
- Your loved one's doctor -2
- Articles on websites (such as WebMD.com) -3
- Internet message boards/support groups/chat rooms -4
- News media -5
- Spanish news media (ask of Spanish-speakers only) -6
- Medical journal articles -7
- Friends -8
- Family members -9
- Co-workers -10
- Religious leaders -11
- Advocacy organizations (e.g., Alzheimer's Foundation of America, Alzheimer's Association) -12
- Local support groups -13
- Houses of worship (e.g., temple/church) -14
- Other (specify): _____ -15
- Have not used any sources of information to learn about Alzheimer's disease. -16

INITIAL DIAGNOSIS OF ALZHEIMER'S DISEASE

Now we would like to ask you some questions about Alzheimer's disease and the person you care for. As you answer the next questions, please think back to the time when the person you care for was first diagnosed with Alzheimer's disease.

13a. (440) How long ago was your loved one diagnosed with Alzheimer's disease? **Interviewer if diagnosed less than 1 month ago, please enter "0" months.**

_____ months ago
or
_____ years ago

13b. (445) How long was your loved one experiencing symptoms before he/she were diagnosed? **Interviewer if diagnosed at the same time as he/she began to display symptoms, please enter "0" months.**

_____ months ago
or
_____ years ago

(ASK Q.13c IF GREATER THAN 0 MONTHS BETWEEN SYMPTOMS AND DIAGNOSIS IN Q.13b.)

13c. (480) You said that [INSERT RESPONSE TO Q.13b] months/years went by between the time your loved one started to demonstrate Alzheimer's symptoms and the time he/she was diagnosed with Alzheimer's.

Which of the following, if any, may have delayed the Alzheimer's diagnosis? ***Read list. Select all that apply.***

[RANDOMIZE]

- I or my loved one has little access to health care professional xx-1
- I or my loved one have never been offered a memory screening -2
- I and/or other caretakers were concerned about the potential stigma of a diagnosis of Alzheimer's disease..... -3
- The person I care for was concerned about the potential stigma of a diagnosis of Alzheimer's disease..... -4
- I did not know enough about Alzheimer's disease/did not know how to recognize or make sense of the symptoms..... -5
- The person I care for did not want to visit the doctor -6
- I did not have time to take the person I care for to the doctor -7
- I did not want to face the possibility that something could be wrong with the person I care for..... -8
- I or my loved one could not afford medical care. -9
- I was fearful of the responsibility that would be placed on me as the caregiver.... -10
- I was concerned that a diagnosis would mean disqualification for long-term health care insurance for the person with the disease -11
- I did not understand my loved one's health care system..... -12
- There was little or no information on Alzheimer's in my primary language..... -13
- I or my loved one did not have a health care provider that spoke my or my loved one's primary language -14
- I could not find a health care provider that was my ethnicity/culture..... -15
- I or my loved one did not have health insurance..... -16
- I thought the symptoms were just a part of getting older. -17
- I thought people with Alzheimer's disease are not sane..... -18
- Other (specify): _____ -19
- None -20

14. (490) When your loved one was diagnosed with Alzheimer's disease, how prepared did you feel to deal with this person's future?

- | | |
|--------------------------------------|-------------------------------|
| Very unprepared..... | <input type="checkbox"/> xx-1 |
| Somewhat unprepared..... | <input type="checkbox"/> -2 |
| Neither prepared nor unprepared..... | <input type="checkbox"/> -3 |
| Somewhat prepared..... | <input type="checkbox"/> -4 |
| Very prepared..... | <input type="checkbox"/> -5 |

15. (495) At the time of diagnosis, were there any areas in which you could have used more or better support/information? **Read list. Select all that apply.**

[RANDOMIZE]

- | | |
|---|-------------------------------|
| Emotional support..... | <input type="checkbox"/> xx-1 |
| Financial support | <input type="checkbox"/> -2 |
| Legal support | <input type="checkbox"/> -3 |
| Support/Flexibility from my employer | <input type="checkbox"/> -4 |
| General information about Alzheimer's disease | <input type="checkbox"/> -5 |
| Support/Advice from experienced caregivers | <input type="checkbox"/> -6 |
| Information about treatment options..... | <input type="checkbox"/> -7 |
| Support from family/friends | <input type="checkbox"/> -8 |
| Local resources | <input type="checkbox"/> -9 |
| Support from health care professionals..... | <input type="checkbox"/> -10 |
| Information in my primary language | <input type="checkbox"/> -11 |
| Support from health care professionals who spoke my or my loved one's primary language..... | <input type="checkbox"/> -12 |
| Support from health care professionals who understood me and my family..... | <input type="checkbox"/> -13 |
| Support from my religious leaders/religious community | <input type="checkbox"/> -14 |
| Other (Specify): _____ | <input type="checkbox"/> -15 |
| None; I got all the support I needed. | <input type="checkbox"/> -15 |

PATIENT'S CURRENT STATUS

Thank you for answering our questions about Alzheimer's disease at the time of the diagnosis. For the next series of questions, we would like you to think about the present time.

16. (500) According to your health care professional, what stage of Alzheimer's disease is the person you care for currently in? ***Read list. Select one answer only.***

MCI (i.e. ongoing memory problems but no other symptoms).....	<input type="checkbox"/>	xx-1
Mild (i.e. slight memory loss, changes in speech patterns, mood, or personality, confusion, etc)	<input type="checkbox"/>	-2
Moderate (i.e. increased memory loss, shortened attention span, problems with language, trouble grooming, etc)	<input type="checkbox"/>	-3
Severe (i.e. complete loss of language and memory, increased sleeping, loss of physical coordination, etc)	<input type="checkbox"/>	-4
Other.....	<input type="checkbox"/>	-5
The doctor did not specify the exact stage	<input type="checkbox"/>	-6
Not sure	<input type="checkbox"/>	-7

TREATMENT HISTORY OF PATIENT

17. (565) Which of the following prescription medications for Alzheimer's disease have you heard of? ***Read list. Select all that apply.***

[RANDOMIZE]

Aricept/donepezil.....	<input type="checkbox"/>	xx-1
Exelon/rivastigmine	<input type="checkbox"/>	-2
Razadyne/Reminyl/galantamine.....	<input type="checkbox"/>	-3
Namenda/memantine	<input type="checkbox"/>	-4
Antipsychotics.....	<input type="checkbox"/>	-5
Antidepressants.....	<input type="checkbox"/>	-6
Other (specify): _____	<input type="checkbox"/>	-7
Have not heard of any treatments by name.....	<input type="checkbox"/>	-8

- 18a. (575) How long has your loved one been taking prescription medication for Alzheimer's disease? ***Interviewer if he/she has taken prescriptions for less than one month, please enter '0 months.'***

Months: _____

Or

Years: _____

He/she has never taken prescription medication for Alzheimer's disease..... xx-1

(ASK Q.18b IF EVER ON PRESCRIPTION TREATMENT IN Q.18a.)

- 18b. (585) Which of the following prescription medications is your loved one currently taking to help his/her Alzheimer's disease symptoms? ***Read list. Select all that apply.***

[RANDOMIZE]

- | | |
|--|-------------------------------|
| Aricept/donepezil..... | <input type="checkbox"/> xx-1 |
| Exelon/rivastigmine | <input type="checkbox"/> -2 |
| Razadyne/Reminyl/galantamine..... | <input type="checkbox"/> -3 |
| Namenda/memantine..... | <input type="checkbox"/> -4 |
| Antipsychotics..... | <input type="checkbox"/> -5 |
| Antidepressants..... | <input type="checkbox"/> -6 |
| Other (specify): _____ | <input type="checkbox"/> -7 |
| Not currently on prescription treatment..... | <input type="checkbox"/> -8 |

19. (590) Are you aware of the opportunity for two medications (that work in different ways) to be used together to treat Alzheimer's disease?

- | | |
|-----------|-------------------------------|
| Yes | <input type="checkbox"/> xx-1 |
| No..... | <input type="checkbox"/> -2 |

- 20a. (xxx) Besides Alzheimer's, does your loved one have any other diseases or conditions that require him or her to take prescription medications?

- | | |
|-----------|-------------------------------|
| Yes | <input type="checkbox"/> xx-1 |
| No..... | <input type="checkbox"/> -2 |

(ASK Q.20b IF YES TO Q.20a.)

- 20b. (xxx) When going to purchase medications for your loved one does any one medication take priority over Alzheimer disease medication. Please explain why or why not one medication may or may not take priority over another. ***Probe until unproductive***
-
-
-

DOCTOR-PATIENT-CAREGIVER RELATIONSHIP

21. (605) Which health care professional primarily treats your loved one for Alzheimer's disease?

- | | |
|-----------------------------------|-------------------------------|
| General/family practitioner | <input type="checkbox"/> xx-1 |
| Internal medicine | <input type="checkbox"/> -2 |
| Neurologist..... | <input type="checkbox"/> -3 |
| Psychiatrist | <input type="checkbox"/> -4 |
| Geriatrician/Gerontologist | <input type="checkbox"/> -5 |
| Other | <input type="checkbox"/> -6 |

22a. (340) How involved, if at all, were you in selecting the health care professional that treats your loved one for Alzheimer's disease?

- | | |
|---|-------------------------------|
| Very uninvolved..... | <input type="checkbox"/> xx-1 |
| Somewhat uninvolved..... | <input type="checkbox"/> -2 |
| Neither involved nor unininvolved | <input type="checkbox"/> -3 |
| Somewhat involved | <input type="checkbox"/> -4 |
| Very involved | <input type="checkbox"/> -5 |

(ASK Q.22b IF AT LEAST SOMEWHAT INVOLVED IN SELECTING HCP IN Q.22a.)

22b. (340) What criteria did you use to select this health care professional?

- | | |
|---|-------------------------------|
| They are on my loved one's insurance plan | <input type="checkbox"/> xx-1 |
| They are close to where my loved one lives..... | <input type="checkbox"/> -2 |
| He/she is considered a leader in treating Alzheimer's disease | <input type="checkbox"/> -3 |
| He/she shares the same values as my loved one..... | <input type="checkbox"/> -4 |
| He/she is the same race/ethnic background as my loved one | <input type="checkbox"/> -5 |
| He/ she can speak my or my loved one's primary language | <input type="checkbox"/> -6 |

CAREGIVER ATTRIBUTES AND LIFESTYLE IMPACT

23. (630) How has your life changed since you started caring for someone with Alzheimer's disease? ***Do not read list. Select all that apply.***

[RANDOMIZE]

- I have less time for myself xx-1
 I have less time for my family -2
 I've had to quit my job -3
 I've had to take on less responsibility at work. -4
 I don't see my friends as often as before..... -5
 I have developed closer relationships with my family. -6
 I became a more compassionate person..... -7
 I have developed closer ties to my community..... -8
 I'm not able to go out as often as before -9
 I am more open to asking for assistance. -10
 I have become more anxious, stressed, or burnt-out..... -11
 I have felt abandoned by family..... -12
 I have felt abandoned by friends -13
 I have become more religious. -14
 I have become an advocate for the cause..... -15
 Other (Specify): _____ -16
 My life has not changed..... -17

24. (630) How has Alzheimer's impacted your relationship with your loved one? ***Read list.***

- It has brought us closer than we were before the diagnosis. xx-1
 It has strained our relationship and we are not as close as we were before the diagnosis. -2
 No change in my relationship with my loved one..... -3

PATIENT DEMOGRAPHICS

25. (635) What is the age of the person whom you care for?

_____ years

26. (640) Please indicate his/her gender.

Male xx-1
Female -2

27. (xxx) Where does your loved one with Alzheimer's disease live? ***Read list. Select one answer only.***

- | | | |
|--|--------------------------|------|
| With me | <input type="checkbox"/> | xx-1 |
| At a nursing home/facility | <input type="checkbox"/> | -2 |
| At their house alone | <input type="checkbox"/> | -3 |
| At their house with other people/aides | <input type="checkbox"/> | -4 |
| At an assisted living facility | <input type="checkbox"/> | -5 |
| With another family member | <input type="checkbox"/> | -6 |
| Other place | <input type="checkbox"/> | -7 |

28. (xxx) Have you thought about placing your loved one in a nursing home or assisted living facility?

- | | | |
|-----------|--------------------------|------|
| Yes | <input type="checkbox"/> | xx-1 |
| No | <input type="checkbox"/> | -2 |

29a. (xxx) Do you think you will place your loved one in a nursing home or assisted living facility in the future?

- | | | |
|-----------------------------|--------------------------|------|
| Yes | <input type="checkbox"/> | xx-1 |
| No | <input type="checkbox"/> | -2 |
| It is not my decision | <input type="checkbox"/> | -3 |
| Not sure | <input type="checkbox"/> | -4 |

(ASK Q.29b IF YES AT Q.29a.)

29b. (675) At what point would you place your loved one in a nursing home or assisted living facility?
Read list. Please select all that apply.

[RANDOMIZE]

- | | | |
|--|--------------------------|------|
| When behavior problems arise | <input type="checkbox"/> | xx-1 |
| When my loved one can no longer recognize me | <input type="checkbox"/> | -2 |
| If I feel that I or my loved one is in physical danger | <input type="checkbox"/> | -3 |
| Other (specify): _____ | <input type="checkbox"/> | -4 |

(ASK Q.29c IF NO AT Q.29a.)

29c. (xxx) Why would you not place your loved one in a nursing home or assisted living facility?
Read list. Please select all that apply.

[RANDOMIZE]

- | | | |
|---------------------------|--------------------------|------|
| I would feel guilty | <input type="checkbox"/> | xx-1 |
| I cannot afford it | <input type="checkbox"/> | -2 |

- My family would look down on me for doing so -3
 My religious leaders would look down on me for doing so -4
 It is my responsibility to care for my loved one -5
 The nursing home or assisted living facility has a majority of staff or residents
 who are different in ethnicity or culture from my loved one -6
 Other (specify): _____ -7

(ASK Q.30 IF LOVED ONE DOES NOT LIVE AT A NURSING HOME OR ASSISTED LIVING FACILITY)

30. (xxx) Have you hired anyone to help take care of your loved one while at home – for example an in-home nurse?

Yes xx-1
 No -2

CAREGIVER DEMOGRAPHICS

31. (xxx) Were you born in the United states?

Yes xx-1
 No -2

(IF THEY WERE BORN IN THE U.S. PLEASE ASK 56.)

32. (xxx) What generation was the first in your family to be born in the United States?

Parents -2
 Grandparents -3
 Great Grandparents -4
 I was the first to be born in the US -5
 Other -7

33. (685) Do you live in the same community (within 50 miles) as your loved one with Alzheimer's disease?

Yes xx-1
 No -2

34. (690) Which one of the following best describes the area where you live?

Rural xx-1
 Suburban -2
 Urban -3

35. (xxx) What is your primary language?

English xx-1
Spanish -2
Other (specify): _____ -3

36. (xxx) Do you only speak your primary language with your loved one's health care provider?

Yes xx-1
No -2

37. (xxx) What is your religion?

- | | | |
|----------------------------------|--------------------------|----|
| Christian..... | <input type="checkbox"/> | -1 |
| Muslim..... | <input type="checkbox"/> | -2 |
| Jewish | <input type="checkbox"/> | -3 |
| Do not practice a religion | <input type="checkbox"/> | -4 |
| Other (specify):_____ | <input type="checkbox"/> | -5 |

37 a. If Christian, which religion specifically:

- | | | |
|--------------------------------|--------------------------|-----|
| Roman Catholic..... | <input type="checkbox"/> | -1 |
| Eastern Orthodox | <input type="checkbox"/> | -2 |
| Baptist..... | <input type="checkbox"/> | -3 |
| Church of Christ..... | <input type="checkbox"/> | -4 |
| Episcopalian | <input type="checkbox"/> | -5 |
| Anglican | <input type="checkbox"/> | -6 |
| Lutheran..... | <input type="checkbox"/> | -7 |
| Latter Day Saints/Mormon | <input type="checkbox"/> | -8 |
| Methodist | <input type="checkbox"/> | -9 |
| Pentecostal | <input type="checkbox"/> | -10 |
| Other (specify):_____ | <input type="checkbox"/> | -11 |

38. (xxx) How religious are you?

- | | | |
|-----------------|--------------------------|------|
| Not at all..... | <input type="checkbox"/> | xx-1 |
| Not very..... | <input type="checkbox"/> | -2 |
| Somewhat..... | <input type="checkbox"/> | -3 |
| Very..... | <input type="checkbox"/> | -4 |
| Extremely..... | <input type="checkbox"/> | -5 |

39. (202) What is your marital status?

- | | | |
|-----------------------------|--------------------------|------|
| Single, never married | <input type="checkbox"/> | xx-1 |
| Married..... | <input type="checkbox"/> | -2 |
| Divorced..... | <input type="checkbox"/> | -3 |
| Separated..... | <input type="checkbox"/> | -4 |
| Widowed..... | <input type="checkbox"/> | -5 |
| Living with partner | <input type="checkbox"/> | -6 |

40. (xxx) In which state or territory do you currently live? [RECORD RESPONSE; DO NOT READ LIST]

41. (212) Which one of the following best describes your employment status?

- | | | |
|--|--------------------------|------|
| Employed full time | <input type="checkbox"/> | xx-1 |
| Employed part time | <input type="checkbox"/> | -2 |
| Self-employed | <input type="checkbox"/> | -3 |
| Not employed, but looking for work | <input type="checkbox"/> | -4 |
| Not employed and not looking for work..... | <input type="checkbox"/> | -5 |
| Retired | <input type="checkbox"/> | -6 |
| Student | <input type="checkbox"/> | -7 |
| Homemaker | <input type="checkbox"/> | -8 |

42. (216) What is the highest level of education you have completed or the highest degree you have received?

- | | | |
|---|--------------------------|------|
| Less than high school | <input type="checkbox"/> | xx-1 |
| Some high school | <input type="checkbox"/> | -2 |
| High school or equivalent (e.g., GED) | <input type="checkbox"/> | -3 |
| Some college, but no degree | <input type="checkbox"/> | -4 |
| Associate's degree | <input type="checkbox"/> | -5 |
| College (e.g., BA, BS) | <input type="checkbox"/> | -6 |
| Some graduate school, but no degree | <input type="checkbox"/> | -7 |
| Graduate school (e.g., MA, MD, PhD) | <input type="checkbox"/> | -8 |

43. (232) Which of the following income categories best describes your total 2005 household income before taxes?

- | | | |
|------------------------------|--------------------------|------|
| Less than \$15,000 | <input type="checkbox"/> | xx-1 |
| \$15,000 to \$24,999 | <input type="checkbox"/> | -2 |
| \$25,000 to \$34,999 | <input type="checkbox"/> | -3 |
| \$35,000 to \$49,999 | <input type="checkbox"/> | -4 |
| \$50,000 to \$74,999 | <input type="checkbox"/> | -5 |
| \$75,000 to \$99,999 | <input type="checkbox"/> | -6 |
| \$100,000 to \$124,999 | <input type="checkbox"/> | -7 |
| \$125,000 to \$149,999 | <input type="checkbox"/> | -8 |
| \$150,000 to \$199,999 | <input type="checkbox"/> | -9 |
| \$200,000 to \$249,999 | <input type="checkbox"/> | -10 |
| \$250,000 or more | <input type="checkbox"/> | -11 |
| Decline to answer..... | <input type="checkbox"/> | -12 |

End of Survey. Thank you!