The Subjective Experience of Early On-set Dementia: Voices of the Persons

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"I'm entirely too young to be in Alzheimer's, but I am."

A 54-year-old woman diagnosed with early on-set Alzheimer's disease

Is being diagnosed with a dementing illness at a younger age, below the age of 65, in one's 40's and 50's, a unique experience, different than receiving the diagnosis in the later decades of one's life? Are specific guidelines and services necessary to meet the needs of these younger individuals? Some researchers have suggested that there are differences and advocated for such services (Cox & Keady, 1999; Keady & Nolan, 1997; Sperlinger & Furst , 1994). Others propose that although there are some differences, regardless of age, what all people with dementia and their families really need are services that are responsive to individual needs (Reed, Cantley, Clarke, & Stanley, 2002). Yet, rarely are younger people with dementia directly asked these questions. As Beattie, Daker-White, Gilliard, and Means (2002) point out, the conclusions are based mainly on the perspectives of health care professionals and family caregivers. Thus, in order to truly answer these questions, we need to explore the subjective experiences of people with early on-set dementia, a perspective that has received limited attention.

Alzheimer's disease (AD) is the leading cause of dementia for people 65 years old and older (NIA, 2000). Yet for younger people with dementia, although AD is still a common cause, they are more likely to experience atypical dementias, such as Frontotemporal dementia (FTD), Primary progressive aphasia, Progressive visuospatial dysfunction, and HIV-associated dementia. Thus, memory loss may not be the initial presenting problem; other symptoms such as behavior and personality changes, and language disturbances may occur first, as well as high levels of psychiatric morbidity (delusions and hallucinations) (Ferran, Wilson & Doran, 1996; NIA, 2002; Harris, Snyder, & Mordhart, 2002; Walton, 1999). Also the development of greater depression is associated with a younger age of on-set (Lawlor, Ryan, Schmeidler, Mohs, and Davis, 1994). Therefore, making a proper diagnosis difficult. In addition, caregivers of younger people with dementia report higher levels of burden (Freyne, Kidd, Coen & Lawlor, 1999, Keady & Nolan, 1997; Williams, Keady, & Nolan, 1995). The Alzheimer's Association (2001) estimates that there are approximately 400,000 people in the United States affected just with early-onset AD. To date, there has been no major epidemiological study in the United States that examined the prevalence and incidence of all forms of early on-set dementia. In the United Kingdom, examining two London boroughs, Harvey (1998) found that there were 67.2 out of 100,000 people with early on-set dementia.

A number of researcher's have proposed unique social challenges and issues that younger people with dementia and their families face: workforce/retirement/financial issues (Delany & Rosenvinge, 1995; Keady & Noaln, 1997; Walton, 1999); changing relationships with family: spouse, children & elderly parents (Cox & Keady, 1999; Walton, 1999); awareness of changes (Tindall & Manthrope, 1997); concerns about genetic transmission (Pollen, 1996; Woods, 1999); having more energy/ being more physical active (Delany & Rosenvinge, 1995; Freyne, et al.,1999); extreme feelings of social isolation and being marginalized (William, Keady & Nolan., 1995); being more depressed (Lawlor et al., 1994); issues of self-hood & self-esteem (Reed, Cantley, Clarke, & Stanley, 2002); off-time dependency (Woods, 1999); and boredom and lack of meaningful occupation (Reed, Cantley, Clarke, & Stanley, 2002). Yet, none of these studies provide an in-depth exploration of the person's subjective experience.

Thus, to explore the lived experience of a younger person who has received a diagnosis of dementia and to give voice to their experiences is the first purpose of this study. Specifically the study focuses on the social dimension of the disease, examining how such a diagnosis impacts the daily lives of a younger person. This will broaden, enrich, and give deeper meaning to many of the issues identified above. Additionally, the paper will provide evidenced-based guidelines for social workers working with this population and their families. This is a population that has been ignored by the social work literature. Also, as Beattie, Baker-White, Gillian, and Means state, "Many articles [in other disciplines] calling for specialist service provision were not grounded in empirical research "(2002:208).

Study Design

A qualitative methodology was chosen to provide an in-depth understanding of the subjective experience of younger people with dementia. This grounded theory methodology is chosen when there is limited knowledge about a phenomenon. The words of the participants are used to explain their experiences of living and coping with the disease.

Data Collection

Data was collected from 23 younger individuals with dementia through three methods: focus groups, face-to-face interviews, and on-line interviews. Of the 23 people interviewed, five participated in a focus group session with follow-up interviews, both the focus group and interviews lasted approximately an hour and a half; five participated in interviews only that lasted from one and half to two and a half hours; and the rest participated in on-line interviews, which consisted of answering open ended questions analogous to the questions asked in the focus group and interviews. The on-line participants were asked to return their responses via e-mail within a week, and follow-up on-line dialogue occurred if necessary to clarify answers.

The focus group and interviews were arranged through a local Alzheimer's Association chapter. The focus group was composed of members of a new support group that had recently been established for younger people with dementia and their families. Initially my role was to only observe some of their sessions and conduct follow-up interviews with interested individuals. I presented my proposal to the support group for permission and consent, and the group members decided they would rather participate in a focus group session to answer my questions specifically and voice their concerns together, and then to be interviewed. A separate focus group was also conducted with the family members (the results are not included in this paper). The focus groups were scheduled during the time of the support group sessions at a meeting room in a local health center. Some people were not part of the support group and thus only participated in face-to-face interviews. All interviews were done at the individuals' homes at times that were convenient for them. The purpose of the study was explained again and informed consent received before any of the focus groups or interviews was started. All the interviews were taped with the permission of the participants and later transcribed. Field notes were completed at the end of each interview and focus group and then compared with the transcriptions for accuracy.

There is a self-help inter-net support and advocacy network for people with early stage dementia, the Dementia Advocacy and Support Network International (DASNI). It is from this group that the on-line participants were solicited. I completed their research approval process and then had an announcement both posted about the study on their message board and mentioned in their chat rooms. People interested in participating in the study contacted me directly through e-mail. It was a multi-step process where I first discussed the study with them, answered questions, and sent them an informed consent form via e-mail. If they e-mailed back their consent, then the interview guide was sent, usually as an e-mail attachment, with directions to be completed, if possible within a week and returned via e-mail. If necessary, reminders were sent after two weeks. Twelve people responded through this method; one person returned the questionnaire through regular mail; four others did not return the survey, and one decided not to participate. Four caregivers also participated, but their responses are not included in this paper.

The depth and quality of the narratives did not vary regardless of the method of data collection, much to my surprise. Certainly the benefits of the face-to-face contact, a more personal contact, allowed for a more informal interchange of questions and ideas, allowing more issues to emerge from the interviews. However, the on-line interviews were not "impersonal." Perhaps the anonymity of the medium allowed people to share thoughts and feelings that they may have been uncomfortable to voice in a face-to-face interview. In addition, the asynchronous feature of on-line dialogue gave the person with dementia the extra time (some may have needed) to think out and draft a meaningful response.

Questionnaire Construction

The interview guide was slightly revised depending upon the method of the data collection. It was divided into six sections: 1) living with progressive memory loss at a young age – age differences, changes in lifestyle, most difficult aspects, positive experiences, effect on sense of self; 2) family and social relationships – affect on family relationships (children, siblings, significant other, and parents), friends responses, and available peer groups; 3) impact on work and family finances – work status, financial hardships, occupying of time; 4) physical/mental health issues – overall health issues, affect on emotional health, and concerns about genetic transmission; 5) stress and coping- major stresses experienced, impact over time, coping strategies (helpful and unhelpful); and service/program suggestions; and 6) meaning and motivation – impact of diagnosis on perspective of life, age implications, personal growth experience, discoveries about self; and recommendations for health care professionals related to working with this population.

Data Analysis

Using the analytical strategy suggested by Glazer and Strauss (1967), the transcripts and down loaded on-line interviews were read to develop substantive codes for each interview. This was a four-step process. First, each transcript and on-line interview was first read in its entirety. Then, they were read a second time to develop codes that were grouped into themes, which emerged from the narratives and the interview guide. In order to be considered a major theme the code had to have appeared in over 50% of the narratives and more than once in each of those narratives. Third, a master list of themes from each interview was developed to allow for easy cross-interview examination. Finally, quotes that summarized the essence of each person’s subjective experience were recorded on the master list.

There are many limitations to a qualitative study. The sample is small and the 23 people with dementia in this sample certainly do not comprise a representative sample of people with early on-set dementia. This study also uses a cross-sectional collection of data to examine a dynamic process, the impact of living with a dementing disease. However, qualitative research makes no claim to be representative of the population it is examining. The purpose of this methodology is to present a more in-depth, diverse, and complex picture of a phenomenon that has been previously reported, and identify possible variables that need to be tested and confirmed in larger representative studies. However, from these narratives comes a better understanding of the issues and complexities younger people with dementia grapple with as they struggle to maintain their lives and personal identity.

Sample Characteristics

Table 1 shows the demographic break down of the sample and the method of data collection. The most common diagnoses were AD and FTD, and one person was diagnosed with Huntington's disease (HD). Eleven of the twenty-three people were male; the mean age at the time of the study was 56 with a range from 43 to 68 years, and the mean age at diagnosis was 53 years old with a range from 42 to 63. The occupations were varied, from housewives and factory workers to professors and scientists; however, since computer skills were necessary for over half the respondents most had some college education. Eighteen people lived with a significant other and six had children under 18 in the household. Seven people reported a family history of dementia, eleven knew of no family history of the disease and the rest were unsure. All people interviewed were Caucasian.

Findings

The analytical framework from which these narratives were examined was organized around the experience of living and coping with dementia at a younger age. The eight themes that emerged from the narratives were: difficulties of getting a proper diagnosis, issues of self-hood and self esteem, changing relationships within entire family structure, awareness of changes in self, workforce/retirement/financial issues, extreme feelings of social isolation and being marginalized, off-time dependency, and boredom and lack of meaningful occupation. The issue of loss on multiple levels was intertwined within many of these themes.

Trouble Obtaining Proper Diagnosis (N=14)

AD was once a diagnosis of exclusion, but now with advances it brain imaging and neuropsychological testing it can be diagnosed with 90% accuracy (NIA, 2000). However, being younger and not looking ill made it more difficult for some individuals to receive a proper diagnosis, especially since other types, atypical dementias are more prevalent in younger people. One woman in her early 60's diagnosed with AD explained, "*People tend not to believe that I have anything wrong because I look and sound so healthy. One of my major stresses was getting my doctor to believe that it's more than stress, depression, or burn out. It's easier now that I don't tell her anything about it. I have to get my medicine from my other doctor."* Another woman with FTD explained her physician's reactions, *"When I finally worked up the courage to share my concerns I was discounted immediately because of my age. So instead of support, my fears and concerns were summarily dismissed."*

Issues of Selfhood and Self Esteem (N=21)

This is the theme that emerged with the most frequency and poignancy from the interviews. Multiple parts of people's self-identity were affected. This is best understood through the words of the individuals themselves.

As one woman in her early 60's stated, *"Since my diagnosis I have lost a lot of me, a person who always enjoyed life.*" As one man in his 40's explained, *"I lost everything that defined me as a productive and meaningful man when I had to stop working because of my symptoms. Eight months prior I had to quit driving because of running red lights and beginning to be in fender benders because of cognitive problems and lack of visuo-spatial coordination, and this took the one 'thing' that gave me my most freedom. The whole role in life shifted from being the main breadwinner to now being Mr. Mom."* And as one woman in her 40's eloquently explained, "*I was a bright, energetic, leader in my field and community with three children and a husband who depended upon me. I lost my career, my identity as a professional person, and my ability to support my family. Certainly a person who can not think, has lost and is losing major roles cannot help but have that affect their sense of self."*

Changing Roles/Relationships within the Entire Family Structure (N=16)

Being diagnosed at a younger age with a dementing illness occurred at a time in the family lifecycle of most of the participants when they still held multiple roles in the family structure: spouse/significant other, parent to young children, adult child to aging parents, and sibling. The diagnosis had a ripple affect throughout the family structure from child to aging parent. One woman in her 40's, a business executive living abroad working for a multinational company, now could no longer live on her own and had to move back with her elderly parents. On the other hand, some people’s parents and siblings, who lived out of town were able to deny the diagnosis for a while. As one man in his 40’s stated, *“I guess my family [parents who live out of town] is still in denial.”* However, the reality of living with some one with dementia is not easily escaped. As one man in his fifties stated, *“My wife of 31 years has to become the sole breadwinner in the family. And knowing that I may never be able to see my grandson grow up, hurts a tremendous amount.”* A woman in her 40’s exclaimed:

> *My memory is so bad that my youngest daughter would sometimes write her name all over my hand so that I wouldn’t forget, and not pick her up. And then finally with a mother who could no longer drive their lives were changed dramatically, no longer could I take them to a friend’s house, to Sunday School, or to a mall. While others saw paid help as a marvelous solution, they did not understand the emotional toll it took on my children to have others do what I once did, how it frightened them to have me losing abilities each moth, each year. They were frightened that I was dying long before I had a diagnosis that I was.*
>
> *My life changed in my marriage too. Now my husband is the sole breadwinner, payer of bills, and driver of <u>our</u> children. This [change] was reflected in our marriage of shared responsibility, shared friendship, shared partnership in ever way, including sexuality. It is hard to feel attractive, or appealing when you have struggled all day just to make it through the day. It is hard to believe you are a person who would be wanted when you are nothing like the person your spouse married.*

Yet for some families dealing with this crisis brought them closer together. As one man in his 50's stated about his relationship with his wife, *"I think it [having AD] has brought us closer together. Maybe closer than ever before because of what we have gone through."*

Awareness of Changes in Self (N=19)

There is a debate in the literature about the capacity for people with dementia to maintain insight as they progress with the disease, and there is even ambiguity on how this awareness should be defined (Clare, In Press**)**. Complicating the situation further is that awareness is not an all-or-nothing experience with some people being aware of changes in themselves in some domains, but not in others. This awareness may differ at different times (Cotrell, 1997; Neundorfer, 1997). However, some research has found that younger people seem to be more insightful about the impact of the disease on themselves and their families. The majority of the people in this study were acutely aware of what was happening to themselves and their families. A woman in her early 60's explained, "*The most difficult aspect of this experience is knowing that I have lost a fair amount already…this is the best I will ever be. It's a down hill run."* A man in his early 60's stated, *"This perhaps sounds contrary to the common idea about AD* [that] *victims lose their self-identity and which given time may well happen to me. And what I am more acutely aware of is the uncertainties that other people feel toward me and its impact on me."* A woman in her 40's admitted, *"The hardest part is I can clearly see the devastation this disease has brought into our lives. Each day is filled with such powerlessness, such despair for what I have lost as I see my colleagues go on with their* *lives, as I see them with their children, I watch my children cling to me as they fear the future, as my husband struggles each day to be almost a 'single parent' with me sitting there fills me with such guilt and despair at times. An older person with AD does not bankrupt their young family; wipe out all college funds with nursing home costs. I can handle that I will lose my life, but that my children's mother will die and leave them is unbearable to me. To know that my husband's life will be put on hold for years, in his prime; to know that I will become a burden, and that only my eventual death will release him from years of such a burden is unbearable."*

Workforce/Retirement/Financial Issues (N=14)

Being diagnosed in their 40' and 50's struck many of the people interviewed at the height of their careers, where retirement and saving for retirement were still a very distant thought. Some, as indicated by the quote above, were still in the process of saving for their children's college education. Depending upon the type of job, some people were able to stay on for a while by pairing down the job responsibilities, other could not and had to go one disability, which caused severe financial hardships. In addition, it was often at work when the symptoms were first publicly noticed, when the individual had difficulty completing a familiar task, or had atypical angry outbursts at co-workers, or became lost driving to a regular customer's place of business. One man in his early 60's explained, *"Having to take a 40% reduction in income has had a severe impact. However, we were able to cut expenses and break even now. We need only minor help from our children."* Another man in his 50's said, *"It's such a challenge yet to work out finances. How are we gonna live out the rest of our lives until retirement? My retirement doesn't kick in until I am 60, I think I am 55, my disability payment is not very big."* A woman in her 40's described the worsening situation at work. "*My disease may have subtly started over 10 years ago when I uncharacteristically started to have outbursts of anger and aggression towards a doctor I worked with in the emergency room. I had previously never displayed any aggression to any of my co-workers*. She switched jobs, companies and even locations and explained, *"They though put up with my angry outbursts and crying spells for high sales performance. But slowly my life began to come apart. After [another] move I found it difficult to learn my new address and telephone number. I would dial a phone number [at work] and by the time someone answered I would forget whom I needed to speak to. I was a go getting overachiever before the diagnosis. But now I was not able to get the job done or handle the stress."*

Extreme Social Isolation (N=15)

Many people with dementia regardless of age talk about feelings of being socially isolated, the failure of some friends and family to maintain contact with them because they can not deal with the changes they see in the person. But what makes this different in a younger person with dementia is the depth of the isolation they feel, the feeling of being 'marginalized.' The accepted model of dementia is that it is an "old person's disease;" a younger person with dementia is not 'main stream.' Additionally if one lives into the later decades of life, it is expected that one will outlive many of one's friends. A woman in her 50's explained her feelings of isolation this way, *"I am a very social person. People counted on me and I felt good about it. I love to be with people. It's really hard because all my friends work. I don't have anyone 'to play with.' Now my friend is my TV."* Another woman in her 40's admitted, *I no longer have any friends; they found it too depressing in someone so young. They were unable to watch and understand the* *changes."* Another women in her early 60's poignantly said, "*They [her friends] have all seemed to slowly disappear. When I was first diagnosed I told them about me having Alzheimer's. They all said, 'Oh, what can I do?' I just asked them to remain being my friend; I don't know why they left. It* <u>*hurts*</u> *so badly."*

Off-time Dependency (N=19)

No wants to be dependent. In western society it is an affront to our adulthood. Yet, with age comes some expected dependency, hence the terms, filial maturity and role reversal. But as difficult as it is, that is what is expected, that is 'on- time.' But an unexpected dependency caused by a dementing illness at a younger age is 'off-time' and that adds additional stress for everyone involved. A woman in her 60's perhaps expresses this best. *"Since my diagnosis I have had to give up my job, which I looked forward to every morning. I have had to give up my driving, depending on my husband to drive me everywhere. My husband has to do so many things for me, things that were suppose to be my job."* A man in his 50's echoed similar feelings of dependency. *"I have been forced to take early retirement and for a person who has worked since he was seven years old retirement and financial dependency upon your wife is very difficult to accept."* And a man in his 40's explained, *"I have lost my ability to be a co-parent to my children and a decision making partner. It's almost like I have become the third child."*

Boredom and Lack of Meaningful Occupation (N=15)

For many of the people interviewed the diagnosis meant early retirement, something that was not planned for and thus few plans were in place. Plus there was the added issue of diminishing skills in some areas of functioning, placing limits on the type of activities possible. A woman in her fifties stated her concerns this way. *You think you* *are going to retire at 62, so it's really hard because all my friends are working. It's a long, long day so I try to keep myself busy, but I mean you can only clean your house so much."* One man is his fifties stated, *"I now spend as much time as I can, trying in everyway I can, to find out as much about Alzheimer's as I can and how to fight it. I try to keep my mind as occupied as possible. I have found that on the days I do very little and my mind is not occupied, it is like I can feel the disease progress."*

Thus, from these narratives it appears that being diagnosed with a dementing illness at a young age is a unique experience with different struggles and challenges. This confirms the differences proposed by the researchers and health care professionals in the literature review. Nevertheless, this is does not mean there are not some shared common experiences among people of any age diagnosed with dementia (See Harris, 2002). However, from the person's perspective, having such as diagnosis occur in one's 40' and 50's seems to have added additional stressors, which have a more overwhelming impact upon the whole family system.

Evidenced – Based Guidelines for Practice

Since the data identify some noteworthy social consequences for younger people diagnosed with dementia, the next question becomes are there practice guidelines unique to working with this population that need to be considered when providing services, and are special services needed? Heiser (2002), based on her practice experience, and Keady and Nolan (1997; 1999), based upon their research strongly advocate for such services. Yet Reed, Cantley, Clarke, & Stanley (2002), based on their evaluation of a specialized service for younger people with dementia that included the perspectives of 22 consumers of the service do not make that recommendation, focusing more on the overall importance of recognizing individuals needs. Below are recommendations that emerged from this study's interviews. The suggestions can be divided into two groups: suggestions that pertain specifically to early on-set dementia and general comments that appear to relate to people with dementia regardless of age of on-set.

Practice Guidelines Related to Early On-set Dementia

Assessment

- Social Workers need to listen to and not discount symptoms merely because of the person being younger.
- Behavioral and personality changes, and psychological disturbances may be the initial presenting symptoms before memory and cognitive impairments, so better diagnostic services for younger people with dementia are imperative.
- Younger people with dementia need to be treated as equal partners in their medical care; this is a crucial generational difference.

Treatment

- Many younger people with dementia have a need or and should be given opportunities to take a proactive role in dealing with this disease.
- Concerns about genetic transmission should be acknowledged and referrals to genetic counselors made, as this is a more common occurrence in early on-set.
- Social workers need to understand that the people diagnosed with early on-set dementia are younger and healthier, and should not be stereotyped with people's "usual" perceptions of AD.

- There is a tremendous need for various types of <u>peer</u> support groups for younger people.
- More written and on-line information is needed to deal with the unique challenges that younger people and their families will face.
- Social Workers should be aware of the enormous impact the disease has on the entire family system, especially children.
- Financial counseling needs to include how being diagnosed at a younger age will affect health and life insurance policies.
- Diagnosis at a younger age can bring couples and families closer; it does not always pull families apart.

Practice Guidelines Regardless of Age of On-Set

Assessment

- Depression is a common reaction and should be recognized and treated.
- There is a need for counseling, especially grief counseling for both the person and family members.
- The need to be treated with respect and dignity is paramount.

Treatment

- Disclosure of diagnosis to family and friends should be encouraged.
- Being involved in productive, meaningful activity is essential, instead of the alternative of waiting for an eventual death.
- Social Workers need to recognize that help certainly is needed, and responses are slow, but coping is possible.
- People with dementia can face adversity and build upon their remaining strengths.

- Many people with dementia are still actively engaged in life.
- The importance of instilling a realistic hope throughout the course of the assessment and treatment is essential.

From reviewing the practice guidelines above, it is clear that younger people with dementia have some special issues that need to be considered and addressed by social workers. Two areas in particular become apparent. The need for socializing opportunities with and social support from others of a similar age, either through support groups, day programs, or more informal gatherings, such as an Alzheimer's Café (Meisen, 2002). Secondly, social workers who provide services to the dementia population and their families need to have some special training about the unique challenges and issues younger people with dementia and their families face. It seems essential that there should be an early on-set expert/advocate available on the program staff of all Alzheimer's Association offices. Also dementia-training workshops for all health care professionals and family members should include as part of their standard procedure, a training module on working with younger people and their families focusing on many of the themes voiced in this paper. What also becomes clear from the data is that younger people with dementia share some of the common experiences of all people, regardless of age, who share the diagnosis. Their unique challenges are added on top of these experiences.

Conclusion

Let us return to the original questions that guided this study, which were mentioned in the opening paragraph of this paper. Is being diagnosed with a dementing illness at a younger age a unique experience? Are specific guidelines and services needed? From these narratives, it is clear that younger people with dementia experience unique social challenges beyond that of people with late on-set dementia. These changes have far reaching effects on them and their families, changes effecting self-esteem, family relationships throughout the entire family structure, workforce and retirement issues, feelings of social isolation, dependency, and lack of meaningful occupation. Though there are some similar experiences with people of all ages who have dementia, the extent and depth of the impact is greater for younger people and their families. The stresses are greater. In addition, many younger people are very aware of the ramifications of this disease on themselves and on their family members and need to discuss these concerns with peers. Some specialized services that provide peer socialization are needed. Thus, social workers need to be educated about these issues and routinely screen for them in their assessments. More workshops focusing on these issues of younger people with dementia need to be developed.

When friends and family members of the 23 people with early on-set dementia I interviewed learned of the diagnosis, almost word for word the initial reaction reported was, "You are too young to have dementia!" Thus reaffirming that the current assumption that dementia is defined as an old person's disease. Although the definition of dementia has changed overtime (Berrios, 1997), its correlation with the aging process has not. The testimony of the people who participated in this study challenge us to expand out understanding of dementia, to listen to their narratives and to expand our services, but most of all to recognize them as intelligent people who are still engaged in life. As one woman eloquently explained as she concluded our interview, "Remember we are struggling to still be the people we have spent our lives becoming."

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Table 1: Characteristics of Participants (N=23)

Sex	Age	Diagnosis	Age at diagnosis	Living Arrangements	Family History	Occupation/ Previous Work	Data Collection
F	63	AD	60	Spouse	Yes	Teacher	On-line
F	63	Degenerative dementia	58	Spouse	No	Child Care Provider	On-line
M	57	AD	52	Spouse	Yes	Social Worker	Focus/Interview
M	62	AD	58	Alone	No	Professor	On-line
M	68	AD	59	Spouse	No	Salesperson	Focus/Interiew
F	62	AD	58	Friend	Yes	Teacher	Focus/Interview
F	53	AD	51	Spouse	No	Factory Worker	Focus/Interview
M	63	AD	61	Spouse	?	Engineer	On-line
M	55	AD	54	Spouse	Yes	Salesperson	On-line
F	61	AD	59	Spouse	No	Factory Worker	Interview
F	59	AD	55	Spouse	?	Housewife	Interview
F	54	AD	53	Alone	Yes	Book keeper	Interview
F	51	FTD	46	Spouse	Yes	Business owner	On-line
F	47	FTD	44	W/parents	?	Business Executive	On-line
F	53	MCI, Benign Tumor	49	Significant other	No	Physician Assistant	On-line
M	66	FTD	63	Spouse	Yes	Engineer	On-line
F	46	AD	43	Spouse/children	No	Professor	On-line
M	45	HD	41	Spouse/children	?	Businessman	On-line
M	52	FTD	49	Spouse/child	?	-----------	On-line
M	61	AD	57	Spouse/child/ mother	No	Scientist	Focus/Interview
F	60	AD	56	Spouse	No	Housewife	Interview
F	43	FTD	42	Spouse/child	No	Housewife	Interview
M	49	FTD	47	Spouse/children	No	------------	On-line