Published in final edited form as:
Alzheimer Dis Assoc Disord. 2010 ; 24(Suppl): S42–S48. doi:10.1097/WAD.0b013e3181f14ad5.

Seeking a Diagnosis for Memory Problems: The Experiences of Caregivers and Families in Five Limited English Proficiency Communities

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Background

Individuals' knowledge about an illness is generally linked to what they do about it. The literature looking at health behaviors (Leventhal et al., 1984) and mental health literacy (Jorm et al., 2000), suggest that people attempt to understand their symptoms based on what they know about an illness, and that in turn affects their recognition of a problem, whether to seek help, manage or consider prevention. (Jorm, 2000; Jorm et al., 2000; Werner, 2003 and 2004). Culture influences how people define, perceive, and respond to illness and explains variations in illness related behaviors (Andrulis, Brach, 2007; Chrisman, Kleinman, 1983).

It is estimated that 5.3 million Americans are affected by Alzheimer's disease or a related disorder (ADRD) (Alzheimer's Association, 2009), regardless of their ethnic background (Ferri, 2005). Aging is the biggest risk factor for Alzheimer's disease. Since the older adult population is the fastest growing age group in this country, the number of persons with Alzheimer's disease (AD) is expected to triple by 2050. Attention to knowledge of ADRD has grown due to these demographics. Existing studies reveal variations in areas of knowledge and a tendency to normalize memory loss across racial and ethnic groups (Barrett et al., 1997; Roberts, Connell, 2000); or hold alternative conceptions of dementia (Ayalon, Area'n, 2004; Connell et al., 2007; Dilworth-Anderson, Gibson, 2002; Hinton et al., 2005; Jones, et al., 2006).

In recent years, there have been ethnographic studies that have explored the conceptualization of dementia in minority communities. A review of these studies found that minority or Euro-American cultures view memory loss and confusion as signs of normal aging or in other non-bio-medical terms (Hinton, et al., 2005). Understanding how individuals perceive ADRD can help us identify what influences the development of accurate and misleading conceptions about the disease, who is at greater risk of poorer knowledge, and who needs further education (Connell et al., 2007). Prior studies have examined factors such as education, concern about developing ADRD and exposure to the disease; concluding that more educated individuals have higher levels of disease knowledge (Ayalon and Area'n, 2004; Edwards et al., 2000; Price et al., 1986).

An essential first step to managing an illness is making a diagnosis. Pharmacologic and non-pharmacologic interventions may help the person with dementia and caregiver cope with symptoms and improve overall well-being (Mittelman, 2007; Schulz, 2005; Bianchetti, 2006). With early detection, reversible causes of cognitive impairment can be identified and treated earlier, improving functioning; however, ethnic elderly are less likely than non-ethnic elderly to have access to or use education, diagnostic services, follow-up treatment and care (Alagiakrishnan, 2008). . Lee, Lee, and Diwan (2009) determined that views of stigmatization and normalization of AD combined with cultural norms can be barriers to early recognition and intervention.

According to the Coalition of Limited English Speaking Elderly (CLESE) in Chicago, it is estimated that approximately 250,000 persons age 60 and older who do not speak English well or at all live in the Chicago metropolitan area. Based on current prevalence estimates, approximately 20,085 Limited English Proficiency (LEP) elders in the Chicago metropolitan area have Alzheimer's disease or related disorders (ADRD). Limited English proficiency (LEP) communities or immigrant communities are often identified as "vulnerable populations"; i.e., groups at increased risk for poor physical, psychological, and social health outcomes and inadequate health care (Aday, 2001). Social and political factors that influence immigrants' vulnerability include 1) socioeconomic background, 2) immigration status, and 3) stigma and marginalization (Derose, et al., 2007; Hinton, et al., 2000). There is very little research regarding the extent of AD knowledge specifically among limited English proficiency communities

Illinois residents, separated from the dominant cultural group by language and diverse ethnic beliefs, have unique challenges in their attempts to access appropriate providers for aging network services and ADRD specific services. As a result, the Illinois Department of Public Health (IDPH) sought and received two Alzheimer's Disease Demonstration Grants to States (ADDGS) (2001-04 and 2005-08). Collaborative partnerships were established among the Cognitive Neurology and Alzheimer's Disease Center (CNADC) (a National Institute on Aging funded Alzheimer's disease center) at Northwestern University's Feinberg School of Medicine, the Coalition of Limited English Speaking Elderly (CLESE - an organization of fifty Chicago area organizations representing twenty language groups), and the Alzheimer's Association – Greater Illinois Chapter, to implement the goals and objectives of the ADDGS, thus establishing a 6-year collaboration. During these two, three-year grant projects, this partnership provided community and professional education programs to raise awareness of Alzheimer's disease and related dementias in the following Chicago's limited English proficiency communities: Chinese, Korean, Polish, Russian, and Spanish speaking groups (2001-04) and Arab, Assyrian, Bosnian, Hindi and Urdu populations (2005-08).

The demonstration projects engaged ethnic community agencies already involved in providing aging network services (case management and direct care) to LEP older adults. Agency personnel received education on Alzheimer's disease and related disorders, how to recognize and screen for persons with memory loss and the benefits of early diagnosis, treatment and support for families. Persons identified with memory problems and not been seen by a physician, were encouraged to seek an evaluation to determine the cause of the problem and to receive treatment. Simultaneously, ethnic agency personnel identified primary care physicians (PCPs) who cared for the majority of older adults in their caseloads and who spoke the respective language. The Northwestern CNADC then provided these PCPs with a manual of diagnostic guidelines and cognitive screening tools developed specifically for this project to assist doctors in recognizing and diagnosing cognitively impaired individuals. Translated dementia education and caregiver materials were provided to the physicians for the caregiving family members.

By the end of the 2nd year of the second ADDGS project (2005-08) in the Arab, Assyrian, Bosnian, Hindi, and Urdu communities, 267 persons with cognitive impairment were identified, connected with homecare services to which they were entitled and offered free registration in the Safe Return Program. Twenty-one PCPs in the respective communities were identified and provided dementia protocol and diagnostic guidelines. However, out of the 267 individuals who were identified as having cognitive impairment via the cognitive screening conducted by the ethnic agency, only 36 or 13% agreed to a diagnostic evaluation.

Project Goals

Additional funds were sought for the purpose of exploring why those identified persons with cognitive impairment in these five LEP communities did not seek a diagnostic evaluation. The goals of this project were 1) to obtain an understanding of how 5 LEP community groups conceptualize dementia, and 2) to understand reasons why persons in these 5 LEP communities seek or do not seek an evaluation for cognitive impairment.

Project Methods

The qualitative methodology used in this study was a combination of observation and interview. The proposed sample consisted of 50 family caregivers of those enrolled in the ADDGS project; i.e., ten from each LEP community (Arab, Assyrian, Bosnian, Hindi and Urdu) during 2005-08. Each community recruited 5 families who had agreed to pursue an evaluation for cognitive impairment and 5 who had refused evaluation. Chicago based ethnic agencies involved in identifying participants for this study were: Arab American Family Services, Metropolitan Asian Family Services (Bosnian, Hindi and Urdu) and Assyrian National Council.

Approval was sought and granted by Northwestern University’s (NU) Institutional Review Board (IRB). The interviewers from each of the 5 language groups were required to undergo Human Subjects Training before beginning their interviews. Due to the fact that these interviewers were generally unfamiliar with the research process and many were not computer savvy, taking the customary on-line human subjects training initially presented a barrier to their participation. The NU-IRB facilitated this community based participatory research effort and held a human subjects training session for all interviewers.

A representative from each language group identified 10 families (5 who had sought an evaluation and 5 who had not sought an evaluation) and scheduled appointments in their homes. Informed consent was then explained and signed prior to beginning the interview. The interviewer took careful notes during and immediately following each interview. The interview questions (see appendix), developed collaboratively with the ethnic agency staff and project consultant, were used to guide the discussion.

The interviewer’s notes were then sent to the PI for analysis. The methodology used in this analysis was grounded theory, an inductive research method in which the theory is developed from systematically analyzed data (Strauss & Corbin, 1990). The PI coded the interviews for emerging themes and the project consultant assisted in reviewing the data for inter-individual and inter-group variation.

Results

The resulting sample total was 48. The Assyrian language group submitted 7 of the required 10 interviews and the Arab community submitted 9 of the 10. All of the interviews took place with a single primary caregiver with the exception of two interviews in the Urdu community where the dyads of son/daughter-in-law and another a daughter/daughter-in-law were interviewed together. Of the 48 participants, 27% were male and 73% female. Respondents were primarily daughters (20) or daughters-in-law (10) for a total of 63%. Eleven or 23% were sons. There were 4 spouses (8%), and 3 grandchildren (6%). Length of time in the United States for caregivers was an average of 15.5. years. Care receivers had a history of memory problems for an average of 5 years; however, caregiving had been occurring for an average of 9 years. Interviewees were trained on basic interviewing techniques and instructed to keep careful notes during and following the interview. Several interviewers discussed their reluctance to take notes during the interview for fear of offending the participant; therefore, wrote notes immediately following the interview.

Conceptualization of Memory Loss and Alzheimer's Disease

Respondents from all ethnic groups indicated that the term "memory loss" and "Alzheimer's disease" engendered sorrowful and sad feelings for the person experiencing symptoms. Alzheimer's disease brought to mind "forgetfulness", "childish thinking and behavior", a "poor quality of life" and "fear" of getting the disease themselves.

When asked what they believed CAUSED MEMORY LOSS, the majority of respondents stated the following in order of frequency:

* Stress, depression, trauma, life hardships

* Old age

* Medication side effects

One respondent stated "She lost her son and husband in the Bosnian war – it is family problems like that these that cause stress in combination with old age". Another in the Urdu community responded the problems are due to a "disturbed family life" and in the Hindi community "due to tension caused by younger daughter living in India and losses of family members". Many believe it is a combination of these things – "old age and stress". For example, a respondent in the Assyrian community stated

> "Age combined with stress, the stress of hard working people, and also the tragedies in life, like losing a loved one. I believe that war has an impact on peoples' lives that leads them to depression and then to memory problems."

Several respondents added medication side effects to their belief of the cause. One Arab respondent stated –

> "People who take lots of medications, I think can cause memory problems…not being healthy, struggles and hardships throughout their lifetime and loneliness."

Those Who Did Not Seek An Evaluation For Memory Loss

Analysis of the interview data provided by the ethnic community interviewers indicated that those who did not seek an evaluation believed memory loss to be a part of normal aging. They found other family and social problems to be of more concern, and/or had a negative past history with doctors. One respondent explained,

> "I have always thought that there would not be much help in taking my father to a doctor for the memory problems because I think it is his age….if this is a normal age problem, it's not a big deal. Also, we were in denial that this is a concern. We didn't think much of it. We thought of it as part of aging and nothing else."

If they believed that tension and stress caused the memory problems they were less likely to seek an evaluation; e.g., this Hindi daughter explained, "Everything that is happening with her memory is due to tension…what is a doctor going to do?" One respondent stated, "There are more personal problems that I don't want to go into detail at this time. They are bigger concerns than my mother-in-law's memory loss." Another stated, "My husband is unemployed and everyone relies on me for the sole source of income – there is constant worry about money". And another responded, "Dealing with a mentally retarded brother-in-law has made life difficult." One respondent indicated, "We felt that her memory loss was due to old age and not a concern" in addition to, "The doctor can't do much to bring my father's memory back". Another, a son from the Bosnian community was more forthright in stating,

> "I don't appreciate American doctors because I don't believe they have the knowledge to treat people in the proper way. They have a completely different approach to medicine than European doctors, who work more on preventative medicine. American doctors work on treating symptoms which never leads to complete healing and resolving the problems….doctors want to make money by selling prescription drugs which cause new diseases, illnesses. It just worsens physical and mental health conditions of the patients….The process of going to doctor is a painful, time consuming, wasteful adventure with no results".

Those Who Sought an Evaluation for Memory Loss

Those who sought an evaluation did so primarily because they wanted treatment to slow the disease, to get help for bothersome symptoms, and/or were in pursuit of a cure. One respondent explained,

> "We decided to go because my mother-in-law had an incident that occurred when we were overseas when all of a sudden she started to blame and accuse her grandchildren of stealing her private and personal items including small amounts of her savings. She also began to misplace her things and blame every member of the family that they deliberately took it away from her."

Another respondent stated,

> "I thought maybe the doctor would tell us things to make it easier (to understand better) to live with these problems, also maybe he could help stop the progression of the memory problems."

Another respondent revealed,

> "Seeing my Mother suffering, like crying, depressed and not sleeping enough. I could not deal with the situation alone and needed professional opinion hoping to find ways to help her".

Experience in the Doctor's Office

Respondents who took their family member to the doctor expressed an overall positive experience. Negative experiences appeared to be related to differing expectations of what could be done. For example, one respondent stated,

> "The visit was very helpful, very informative, just like counseling. The doctor said we have to be more understanding of the disease and understand her feelings, pay a lot of attention to her feelings, be sensitive towards her and don't argue and fight back with her against her memory problems and just to redirect her into a better mood or safer environment….organize our life style to fit her way of life with her memory loss".

One daughter indicated learning a new way of coping and living with the illness as a result of the evaluation, stating,

> "It was helpful because it confirmed that what was wrong with him and that the memory loss problems are not of his doing. I now realize that he cannot be blamed for his actions. For now, we need to try and help him and cope with this disease."

Another stated, “I was happy to see I’m not alone. It gave me strength.”

However, those upset with the evaluation process indicated,

> “It was depressing and emotionally disturbing….my mother-in-law was reminded of her past and just kept talking about her past life as if it was today. I felt so sorry for her. To see her like this was so sad and upsetting for me”.

Another stated,

> “The doctor did not give time to go through any testing, procedures. She pushed for scheduling appointments regarding other health issues…she was more concerned about physical health. Her memory problems are now worse than before. The doctor has not given us any new medicine, advice or anything specific to this condition.”

Another respondent stated that the visit went well; however, she acknowledged the limitations of medical intervention,

> ”I wasn’t surprised when the doctor told me that my husband had Alzheimer’s disease. I was very pleased with the doctor’s assessment. The visit went well and the doctor prescribed medications, but they didn’t help his condition much. The memory loss increased over time. The doctor increased the medications and the condition kept worsening.”

Coping with Symptoms

Both those who sought and did not seek an evaluation experienced or coped with symptoms in a variety of ways; i.e., caregivers in both groups admitted feeling overwhelmed, some took a more practical problem-solving approach to care and some expressed a sense of duty and honor. For example, in terms of feeling stressed by caregiving, one respondent summed up her feelings by stating – “I feel tired, lost overwhelmed and worried all of the time….it is hard to adjust to it” and another stated, “I am always panicking and worried because they are always forgetting something or I fear they might do something dangerous to themselves”.

An example of a more problem-solving approach was expressed by another respondent,

> “The way we cope with Mother’s memory loss is by not leaving her alone. All of the family keeps coming and going. We keep her socially active, we constantly keep talking and conversing with her which she enjoys very much. We take her places she likes. She likes to shop, visit family and friends., We constantly do things with her. We feel this helps her not forget and keep her mind active.”

Yet another expressed the time as an opportunity to reciprocate,

> “Life is short and I am happy to take care of my father. Even though it is emotionally and physically exhausting, I love him and wouldn’t change a thing. He is my father and I know he loves me and I would never imagine not to take care of him. It is my honor to take care of my parents. I love to be with them. To me, this is quality time that I now can reciprocate for the times I was working and hardly spent time at home. I now have the opportunity to pay them back for all the hard work they did to raise us.”

However, those who took their family member to the doctor and for which it was a positive experience, felt that it helped them modify their communication. One respondent stated, “For instance, that if she repeats some questions over and over, now I change the subject and divert her attention towards something else”. Others indicated, “I treat her with patience, with more respect"; "I don't get angry if she repeats over and over the question"; "I am more understanding and patient".

When questioned regarding what has been most helpful, the majority of respondents focused on social support, family, the Chicago Department on Aging and ethnic agency services, and the Alzheimer's Association's Safe Return program. Those who had a positive experience with getting an evaluation felt this was particularly helpful along with the education regarding the disease process.

Discussion

This study was conducted to help determine how 5 LEP communities conceptualize dementia and how that conceptualization impacts the decision to seek or not seek a diagnosis for symptoms of cognitive impairment. The study was a successful community based participatory research (CBPR) effort between a grassroots community service organization (CLESE) and a university-based Alzheimer's disease center (Northwestern University CNADC). The interviewers from 5 ethnic agencies developed interviewing skills and human subjects training to gather the data.

Ethnic agencies also informed the idea for the original proposal, the methodology and results interpretation. For example, the PI originally proposed we hold 10 focus groups in each language group: five groups of those who sought an evaluation and 5 who did not seek an evaluation. However, this was modified due to ethnic agency concerns that family members would be reluctant to discuss "personal and private" family information in front of others. They believed that the family would be more likely to answer interviewer's questions in private with a person who spoke their language.

Another modification was the issue of audio-taping the interviews. Again, the ethnic agency representatives were adamant that the family would not be forthcoming or even allow the conversation to be tape-recorded. We ultimately agreed that the interviewer would take careful notes during and immediately after each interview to capture as much of the data as possible. Subsequent meetings were held during the first three months of the grant to review the interview guide, the proposed informed consent, and other procedural issues.

Beliefs regarding Memory Loss

Overall, as found in previous studies, there was a sense that memory loss was explainable and normative; in this study, due to aging, reaction to medication or psychological stress and trauma experienced by war, family problems or the immigration experience. Additionally, the majority of individuals in this sample believed that memory loss evokes a feeling of sorrow for the affected person. The data indicates that families can live with these normative changes and may be reluctant to seek physician assistance until the symptoms become unmanageable.

Coping with Caring for Person with Memory Loss

There is variability among how families from these 5 ethnic communities are coping with the illness. Some are burdened. Others are finding meaning in the experience. Many express feeling both.

Seeking an Evaluation

The qualitative analysis revealed that the primary predictor of whether someone was taken to a doctor for dementia symptoms was dependent upon other psychosocial stressors in the family that were of more concern than the person with memory loss. Other reasons why those who sought an evaluation included wanting treatment to slow the disease, seeking help for bothersome symptoms, and/or they were in pursuit of a cure. They also recognized they could not do it alone. For those who sought a diagnosis, the majority indicated that the symptoms became so difficult to manage that they could no longer cope without some intervention. In contrast, those who did not seek an evaluation indicated there were other concerns that took precedence over the person's memory loss; i.e., other family members' health, employment (or lack thereof), juggling work and raising children and dealing with financial hardship. While they admitted that their family member with memory problems was of much concern it was not clear to them why going to a doctor would be helpful, calling it "a waste of time," stating, "the doctor can't do much to bring my father's memory back", or they attributed the changes to normal aging, "my mother is old. " They also attributed the memory loss to the stress and tension the older adult had experienced. In spite of these beliefs, however, they seemed to recognize the fact that their family member needed ongoing supervision and care and they were providing this.

Experience at the Doctor's Office

Most found the doctors' visits helpful, particularly if the doctor took the time to provide counseling and education regarding the disease and alternative communication strategies. The difference in the experiences of those who sought an evaluation appears to stem from the families' expectations of the doctor. Those who wanted a cure or treatment to make their family member better, were disappointed and more negative about the appointment. However, those who sought help for symptoms and how to better live with the changes they were experiencing had a more positive and helpful encounter. As stated, this was coupled with the doctor taking the time to discuss the illness with the family and provide counseling and education. Families appeared to particularly benefit from the opportunity to talk and understand how to best communicate with their family member. As a result of getting support and education from their doctor, they modified the way in which they interacted with their family member.

Study limitations

There are several limitations to this study. First, it is a small convenience sample and second, the narrative data was dependent on the memory and note-taking of the interviewer instead of transcriptions of audio-recordings. Additionally, and perhaps most enlightening was the discussion of the analysis with the interviewers in a meeting where the results were presented for discussion. What emerged at this meeting was a surprising portrayal of stories and anecdotal descriptions of very burdened families caring for severely cognitively impaired older adults with what they felt was very little support. The intensity of the discussion richly complemented the data, from which similar themes emerged. The interviewers explained that they were directed by families to not share on paper or in any formal way, some of the more painful and what they felt were "shameful" parts of their family stories. While the family member felt it was okay to discuss with the interviewer, they did not want this information to be explicitly shared with the university or the "outside world". Therefore, the difficulty capturing the data is not only a limitation, it reveals the profound stigma of Alzheimer's disease in these communities.

In spite of these limitations, it is believed that this study further adds to our understanding of how dementia is conceptualized, managed and treated in limited English proficiency communities. It illustrates a complex blend of culture, language, behavior and knowledge in the experience of caring, responding to and making decisions for an aging and cognitively impaired family member.

Conclusion

There is much variability in how families in LEP communities cope with symptoms of dementia. The results of this study indicate that getting an evaluation for symptoms, particularly if it is a positive experience in the doctor's office, helps in coping with and managing difficult behaviors. Further health promotion and education on AD is needed to increase awareness of the benefits of early diagnosis, treatment and care. Further exploration is needed on the adequacy of services in these communities (AD and non-AD related) for both diagnosed person and family.

Acknowledgments

The authors wish to thank the community partners/interviewers from the five LEP communities - Kousar Barkatullah, Fatima Borjanovic, Asma Khan, Chintal Mehta, Amena Nayeem, Hamida Parcic, Najwa Saleh, Shoshan Sarkis, Jahnavi Soni, Ramiza Vukic, Wafa Zegar and the previous CLESE executive director involved in the writing of the initial proposal to Chicago Community Trust, Beth O'Grady, who retired during the course of the project.

The PI of the study, Darby Morhardt, would like to thank Jason Karlawish, MD at the University of Pennsylvania Alzheimer's Disease Research Center whose conversations and previous work provided inspiration for this project.

Financial Disclosure: This research was supported by a grant from the Chicago Community Trust to the Coalition of Limited English Speaking Elderly and in part by Alzheimer's Disease Core Center grant AG13854 from the National Institute on Aging to Northwestern University Feinberg School of Medicine and a Regional Alzheimer's Assistance Center grant from the Illinois Department of Public Health.

Appendix

APPENDIX:

Interview Guide

Thank you for participating in this study. I am going to ask you some questions about memory problems and growing older. As you answer these questions, I will take some notes for accuracy and so I don't forget. It is important that I have written what you said and not what I think you said.

1. What words come to mind when you think of an older person with memory problems?
2. What are the words that come to mind when you think of Alzheimer's disease?
3. What do you think causes these problems?
4. Are these memory changes or problems a big concern for families like yours?
5. Are there problems you are dealing with that are of more concern to you than your family member's memory problems?
6. What kinds of things do families like yours think about when they are deciding whether or not to take their family member with memory problems to the doctor?
7. What went into your decision to take your family member/or NOT take your family member with memory problems to the doctor for an evaluation?
8. Can you tell me about how the visit went?
9. Was it helpful? Why or why not?
10. How are you now coping with your family member?

11. What has been most helpful to you?

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