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# Patients' attitudes of dementia screening across the Atlantic

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## SUMMARY

**Background—**Dementia is a common and growing global public health problem. It leads to a high burden of suffering for society with an annual cost of $100 billion in the US and $10 billion in the UK. New strategies for both treatment and prevention of dementia are currently being developed. Implementation of these strategies will depend on the presence of a viable community or primary care based dementia screening and diagnosis program and patient acceptance of such a program.

**Objective—**To compare the acceptance, perceived harms and perceived benefits of dementia screening among older adults receiving their care in two different primary health care systems in two countries.

**Design—**A Cross-sectional study.

**Setting—**Primary care clinics in Indianapolis, USA and Kent, UK.

**Participants—**A convenience sample of 245 older adults (Indianapolis, $n = 125$; Kent, $n = 120$).

**Outcomes—**Acceptance of dementia screening and its perceived harms and benefits as determined by a 52-item questionnaire (PRISM-PC questionnaire).

**Results—**Four of the five domains were significantly different across the two samples. The UK sample had significantly higher dementia screening acceptance scores ($p < 0.05$); higher perceived

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**CONFLICT OF INTEREST**

None known.

stigma scores ($p < 0.05$); higher perceived loss of independence scores ($p < 0.01$); and higher perceived suffering scores ($p < 0.01$) than the US sample. Both groups perceived dementia screening as beneficial ($p = 0.218$). After controlling for prior experience with dementia, acceptance and stigma were marginalized.

**Conclusions—**Older adults attending primary care clinics across the Atlantic value dementia screening but have significant concerns about dementia screening although these concerns differed between the two countries. Low acceptance rates and high rates of perceived harms might be a significant barrier for the introduction of treatment or preventive methods for dementia in the future.

### Keywords

dementia; primary care; screening acceptance; perceived harms and benefits

## INTRODUCTION

The increasing prevalence of dementia is a global concern from both an economic and health policy perspective (Ferri *et al*., 2005). In the United States of America there are approximately 4 million people with a diagnosis of dementia. Estimates for dementia have been reported up to 11% for those over age 65 and up to 47% for those over age 85 (Boustani *et al*., 2003). In the United Kingdom, approximately 750,000 people have a diagnosis of dementia and this will increase to over 1.8 million by 2050. There is an increasing requirement for health and social care provision resulting in higher economic demand for dementia care. The economic burden associated with dementia approaches $100 billion annually in the US and £5 billion ($10bn) in the UK(Brayne *et al*., 2007). Dementia screening may provide a potential mechanism for decreasing this burden by identifying the disease earlier in order to implement treatment and support strategies. The understanding of attitudes toward dementia screening including the perceived harms and benefits, may provide valuable information about potential barriers to this process (Boustani *et al*., 2008).

The source or structure for healthcare funding is often identified as a contributing factor to the quality, cost and acceptance of services provided (Steel *et al*., 2004). Even though the United States spends more of their gross domestic product on healthcare compared to the United Kingdom, there is little evidence of consistent disparity in health outcomes between a private insurance model (US) and a National Health Services model (UK) (Vickrey *et al*., 1998). Experiences related to care coordination, physician-patient relationships, medical errors, use of prescription medications and access to needed care have been identified as common areas that lead to a global perception of dissatisfaction in general health system quality (Blendon *et al*., 2003). Similar comparative concerns develop surrounding the acceptance of screening and disclosing a diagnosis of a disease or impairment such as dementia (Brodaty *et al*., 1994; Byszewski *et al*., 2007; Cahill *et al*., 2006; Connell and Gallant, 1996; Domenighetti *et al*., 2003).

This pilot study investigated the commonalities and differences in perception or attitudes toward dementia screening among older adults in the US and UK. Perception and attitudes toward dementia screening may be influenced by gender, ethnicity, culture, or concerns that

are financially motivated and reflective of the current trends or patterns in a health care delivery system or socioeconomic status (Blendon *et al*., 2003). New strategies for both treatment and prevention of dementia are currently being developed. Implementation of these strategies will depend on the presence of a viable community or primary care-based dementia screening and diagnosis program and the patient's acceptance of such a program.

## METHODS

This study was approved by the Indiana University Purdue University Indianapolis (IUPUI) and the University of Kent Institutional Review Boards. All study participants provided written informed consent to be enrolled in the study.

### Population

The sampling frame consisted of all patients aged 65 and older who were receiving their primary health care services within two health care services from two countries (US and UK).

In the US, the study enrolled a convenience sample of 125 older adults residing in Indianapolis and receiving their care from Wishard Health Services (WHS) from September 2004 through June 2005. WHS includes a 450 bed, university-affiliated, urban public hospital and seven community-based primary care practice centers in Indianapolis. These centers are staffed by 35 general internists on the faculty of Indiana University School of Medicine and 118 internal medicine residents. WHS serves an older population comprised of 69% women, 63% African-American, and 44% with 8 years or less of education (Boustani *et al*., 2005). We excluded patients aged younger than 65, prisoners, patients residing in a nursing home, patients unable to speak English, having a mental health illness such as schizophrenia or bipolar disorder, having a chart-based diagnosis of a memory problem or dementia, and those who had not been seen by a WHS primary care physician within two years prior to the study's initiation. The main reason identified for refusing participation was 'not interested in becoming involved in any research study.'

In the U.K., National Health Service dementia services are organized in a partnership involving Primary care, Older Persons Mental Health Services (OPHMH) and social services (Raising the Standard 2006). Care is provided through three routes: (1) General Practitioners refer to OPMH direct and appropriate members of a multidisciplinary team perform an assessment and devise a management plan. This may include social services involvement; (2) Social services or other secondary care services refer to OPMH; and (3) self- referral to memory clinics.

OPMH consists of multi-disciplinary teams which include psychiatry, psychiatric nurses, psychology, occupational therapy and a social worker. Assessments occur in clinics, assisted living facilities and patients' homes. Care settings range from day centers to inpatient units. 120 patients were recruited by random generation from primary care databases using the same inclusion criteria used by the US study to extract appropriate cases. The reason for the office visit was not identified. Patients so identified were then mailed the information with a stamp requesting them to either contact by phone or return the consent form. All patients

were telephoned to check receipt of the information. Upon receipt of the consent form, an appointment was made for the research assistant to carry out the study questionnaire.

### Data collection (see Table 1)

The Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) questionnaire was used for both the UK and US samples. This questionnaire was designed to capture the acceptance and perceived harms and benefits of dementia screening. Face and content validity for the questionnaire was established through a comprehensive review by 16 clinical researchers in both the US and UK with expertise in dementia care and survey development (Boustani *et al*., 2008). Exploratory factor analysis was used to identify domains for: Acceptance of dementia screening (six items); Benefits of dementia screening (eight items); Stigma of dementia screening (ten items); Impact of dementia screening on independence (6 items); and Suffering from dementia screening (four items). The internal consistency for all subscales of acceptance and perceived harms and benefits had a Cronbach's alpha range of 0.58–0.89. Each study participant, at both the US and the UK sites, completed the questionnaire in the presence of a trained research assistant. Each item was rated on a five-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. The items for each domain are listed in Table 1. Domain scores were calculated for dementia screening acceptance, benefit, stigma, loss of independence, and suffering. Although we were interested in patients' acceptance and the harms and benefits of dementia screening that they perceived, we used the term Alzheimer's disease as an alternative to dementia because our early work showed 'Alzheimer's disease' to be a more readily understood term than dementia.

### Statistical analysis

All items were reverse coded such that a higher score indicated stronger agreement with the statement. Each domain score was created by taking the sum of the reverse coded items and then transforming it to a 0–100 scale by subtracting the minimum score and dividing by the range. We used two-sample *t*-tests to test for differences between the US and UK respondents with respect to these scales. We then used regression models to test for differences in scale measures between the US and UK while adjusting for age, gender, education, and previous experience with AD or memory problems. To adjust for multiple testing on the five domain scales, we performed Hochberg's Step-Up Bonferroni method on the raw *p*-values.

## RESULTS

Demographic characteristics and participants' prior experience with Alzheimer's disease and screening are presented in Table 2. UK participants tended to be older than US patients, and significantly more UK participants were married than US participants. There were also significant differences in ethnicity between the two samples. The majority of US participants were African-American while all but one UK participant was white.

When asked about prior experience with Alzheimer's disease, significantly more UK participants (48%) identified having close friends or relatives who have or had AD when

compared to US participants (27%). Twice as many UK participants thought they had more memory problems than others their own age when compared to the US group. There were no other significant group differences for questions related to prior experience with AD. Both groups were asked if they would like their doctor to examine them yearly for depression with no significant differences between groups for the acceptance of depression screening.

Results of comparing the five domain scores between the two samples are presented in Table 3a. Four of the five domains were significantly different across the two samples when adjusting for age, gender and education. UK participants had significantly higher dementia screening acceptance scores, higher stigma scores, higher loss of independence scores, and higher suffering scores than US participants. However, when controlling for 'friend or relative with AD' and 'belief of more memory problems than others the same age', only the perceived loss of independence and perceived suffering scores were significantly higher for the UK sample. To investigate cultural differences between sites, we conducted a separate analysis controlling for race reported in Table 3b. When comparing white US *vs* white UK, all differences are no longer significant. Differences seem to occur for acceptance and suffering where scores increase by 2 to 3.5 points when excluding African Americans.

## DISCUSSION

Overall, UK participants were more accepting of dementia screening. However, despite the higher acceptance of screening, the UK group considered a diagnosis of dementia to carry more stigma, and greater impact on independence and suffering. Similarities between the US and UK were seen in the mutual perceived benefit of dementia screening. Prior experience with dementia impacted the acceptance scores between the two groups. Having a friend or relative with AD and belief of memory problems marginalized the acceptance scores between the US and UK participants.

Differences were seen in the demographic characteristics of the sample; the most significant being race and marital status. Racial, cultural, and gender support differences may have influenced responses to the questionnaire. The two domains influenced by the race difference were seen for acceptance and suffering. Although there was a negligible point difference for the remaining items, the change in significance may have more to do with sample size differences (50 *vs* 120). Further investigation into these differences with more equitable sample characteristics would be warranted. One factor that was not taken into consideration was the socioeconomic status of the sample which may have impacted their responses to financially oriented questions. The caregiver support dynamics for these participants may have also influenced responses. Although more of the UK participants were married, they indicated a significantly higher perceived loss of independence associated with dementia screening than the US. The perceived role of the spouse as a potential caregiver may be a potential barrier to the screening process.

### Limitations

The convenience sampling for this study limits the generalizability of these results for both the US and UK. The large disparity in the ethnicity also may have confounded the comparison as described in Table 3b. Future comparative research in this area should

emphasize matching on key demographic characteristics to provide a better comparative base. We did not gather the economic or medical burden characteristics from these locations. Characteristics of prior knowledge and experience with AD influence acceptance and perceived stigma associated with dementia screening.

Although there is evidence of mutual perceived benefit, significant differences in acceptance, stigma, loss of independence and suffering associated with dementia screening are evident when comparing older adults from two different countries and health care systems. Older adults attending primary care clinics across the Atlantic have significant concerns about dementia screening. Brayne and colleagues (Brayne *et al*., 2007) identify the need for evidence showing that the benefits for dementia screening outweigh the potential harm. Low acceptance rates and high rates of perceived harms might be a significant barrier for the introduction of treatment or preventive methods for dementia in the future within the US and UK health care systems. Understanding the risks and benefits of early identification from the perspective of patients is one of the most important pieces of information needed to improve the process of early identification. This can potentially lead to the development of an individualized counseling program embedded within the primary care system that would facilitate early diagnosis of dementia and thus set the stage for early intervention where appropriate.

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**Table 1**

PRISM-PC item grouping for the domains of acceptance, perceived benefits and harms of dementia screening

| | |
|---|---|
| | *Dementia screening acceptance items* |
| 1 | Like to know if at higher risk for AD |
| 2 | Like to know if I have AD |
| 3 | Like to be tested for AD with short questionnaire |
| 4 | Like to be tested for AD with blood sample |
| 5 | Like to be tested for AD with CT-scan or MRI |
| 6 | Like MD to examine me for AD |
| | *Benefits of dementia screening items* |
| 1 | Increases the chance to treat the disease better |
| 2 | Family would have a better chance caring for me |
| 3 | Have more time to plan my future |
| 4 | Have more time to talk with my family about my health care |
| 5 | Have more time to talk with my family about my finances |
| 6 | Sign my advance directive or my living-will |
| 7 | Be motivated to have a healthier lifestyle |
| 8 | More willing to participate in research about this disease |
| | *Stigma score items* |
| 1 | Would not want my family to know |
| 2 | Feel humiliated by my family members and/or others who would treat me poorly or laugh at me |
| 3 | No longer be taken seriously |
| 4 | Be considered stupid and unable to do things |
| 5 | Be ashamed or embarrassed |
| 6 | Give up on life |
| 7 | My doctor would not provide the best care for my other medical problems |
| 8 | My doctor and other health professionals would not listen to me |
| 9 | Be concerned that my health insurance company would find out |
| 10 | Be concerned that my employer would find out |
| | *Loss of independence score items* |
| 1 | Not be able to get health insurance |
| 2 | Not be able to get life insurance |
| 3 | Not be able to get long-term care insurance |
| 4 | Lose my home |
| 5 | Be living in a nursing home |
| 6 | Lose my driver’s license and other privileges |
| | *Suffering score items* |
| 1 | Family would suffer financially |
| 2 | Family would suffer emotionally |
| 3 | Be depressed |
| 4 | Be anxious |

**Table 2**

Primary care patients' characteristics at both the US and the UK sites

| | US (*n* = 125) | UK (*n* = 120) | *P*-value |
|---|---|---|---|
| *Demographics* | | | |
| Mean age (SD) | 73.8 (6.3) | 75.3 (6.5) | 0.059 |
| % Female | 60.8 | 51.7 | 0.159 |
| Race | | | |
| % Caucasian | 38.4 | 99.2 | <0.001 |
| % African-American | 60.0 | 0.0 | |
| % Asian | 1.6 | 0.8 | |
| % Some college, university | 21.8 | 30.8 | 0.112 |
| % Live alone | 39.2 | 39.5 | 1.000 |
| % Married | 28.8 | 58.3 | < 0.001 |
| *Prior experience with AD and screening* | | | |
| % Relative or friend with AD | 27.2 | 47.5 | 0.001 |
| % Believe higher risk of AD than others in age group | 8.0 | 9.2 | 0.821 |
| % Think more problems with memory than others same age | 7.2 | 18.3 | 0.012 |
| % Told by doctor have memory problems | 2.4 | 0.8 | 0.622 |
| % Taking medication to help with memory | 1.6 | 0.0 | 0.498 |
| % Don't believe treatment for AD currently available | 34.4 | 31.7 | 0.685 |
| % Accepted screening for depression | 60.8 | 49.2 | 0.073 |

## Table 3

**a. Comparison of primary care patients' domain scores between the US and the UK sites adjusting for age, gender, education* plus relative or friend with AD, more problems with memory for same age****

| | US (*n* = 125) | UK (*n* = 120) | *P*-value* | *P*-value** |
|---|---|---|---|---|
| Mean dementia screening acceptance score (SD) | 60.6 (17.7) | 66.9 (18.0) | 0.015 | 0.053 |
| Mean benefit score (SD) | 69.0 (9.8) | 66.5 (14.5) | 0.218 | 0.310 |
| Mean stigma score (SD) | 37.5 (10.3) | 41.2 (10.3) | 0.018 | 0.088 |
| Mean loss of independence score (SD) | 54.0 (11.4) | 59.6 (11.2) | 0.001 | 0.004 |
| Mean suffering score (SD) | 55.9 (14.5) | 62.3 (13.4) | 0.001 | 0.001 |

**b. US white *vs* UK**

| | US (*n* = 50) | UK (*n* = 120) | *P*-value* |
|---|---|---|---|
| Mean dementia screening acceptance score (SD) | 62.4 (18.6) | 66.9 (18.0) | 0.122 |
| Mean benefit score (SD) | 70.8 (9.8) | 66.5 (14.5) | 0.189 |
| Mean stigma score (SD) | 37.7 (10.7) | 41.2 (10.3) | 0.122 |
| Mean loss of independence score (SD) | 54.0 (12.0) | 59.6 (11.2) | 0.060 |
| Mean suffering score (SD) | 59.0 (12.6) | 62.3 (13.4) | 0.122 |

* adjusted *p*-value for age, gender, education using logistic regression modeling and for multiple comparisons using Hochberg's Step-up Bonferroni method.

** additional adjustments for friend with AD & more problems with memory for same age.

* adjusted *p*-value for age, gender, education using logistic regression modeling and for multiple comparisons using Hochberg's Step-up Bonferroni method.