

# Perspectives of General Practitioners on the Issues Surrounding the Late Diagnosis of Alzheimer's Disease

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Accepted 5 October 2018

**Abstract.** We set out to investigate the insights general practitioners (GPs) have into the early signs and symptoms of Alzheimer's disease (AD), factors that may be responsible for the late diagnosis, as well as their recommendations for early diagnosis of AD. This was a semi-structured, qualitative and audio-recorded interview of seven GPs, from five GP surgeries in Milton Keynes and Luton, using the framework analysis. GPs reported challenges with the current patient's consultation time, a lack of continuity of care, inadequate training, limited support for patients after diagnosis, and poor treatment of the UK's aging population. The study highlights important changes that would facilitate the earlier diagnosis of AD.

**Keywords:** Alzheimer's disease, general practice, GP interviews, qualitative study, semi-structured

## INTRODUCTION

In the UK, primary care (PC) is the first point of contact for patients with almost any health concern. PC patients' data, which are accurate, accrued over a period, present an excellent opportunity for assessing chronic conditions with a long latency period [1]. The data present an opportunity to retrospectively identify patterns in the early signs and symptoms of Alzheimer's disease (AD), for early diagnosis and timely intervention [2]. Importantly, the predictive model in signs and symptoms can be used at the population level as a screening tool for specialist referrals to facilitate the early diagnosis of AD. For this reason, and as part of a feasibility study, we explored the perspectives of general practitioners (GPs) with regards to the current challenges they face in achieving an earlier diagnosis of AD and their recommendations to circumvent these issues. This is

because late diagnosis of AD is documented to result in severe health consequences to individuals affected and their caregivers [3–5], while early diagnosis has been shown to be beneficial. Early diagnosis offers the opportunity for early interventions such as cognitive behavioral therapies and dietary changes as well as the implementation of coordinated care plan, better management of symptoms, patient safety, cost saving and postponement of institutionalization [6–12]; hence, the need to develop an acceptable early detection model that is cheap, non-invasive and applicable to the primary care settings.

This study aimed to explore the perspectives of GPs as to the factors that may be responsible for the late diagnosis of the disease as well as their recommendations to circumvent these.

## METHODS

### *Participants*

Participants included GPs ( $n=4$ ) from Milton Keynes ( $n=3$  males and  $n=1$  female) and Luton

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( $n = 3$  females) using a purposive sample. At the time of the study, participants had at least eight years post qualification each.

Even though the data are anonymized, consent was sought and approved by the participating GPs.

The study sought and acquired a favorable ethics opinion from the Office of the Research Ethics Committee, North of Scotland (16/NS/0034), the University of Bedfordshire Ethics Committee and the Health Research Authority. We have received informed consent from all participants before the commencement of the interviews.

### Procedure

The semi-structured interviews were conducted using an interview guide that was developed based on the relevant literature that emphasized the challenges of under-diagnosis and the need to increase the diagnostic rate as well as the inadequate definition of AD by a single domain [13, 14], including our own systematic review of the literature, which found out the lack of a clear pattern of the signs and symptoms and the general dearth in data on the patterns of presentation preceding the clinical diagnosis of the disease [15] and in consultation with clinical colleagues. The interviews lasted no longer than 30 minutes, and were digitally recorded and transcribed verbatim.

### Data analysis

The audio recorded interviews were analyzed using the framework approach. The transcripts were further checked for accuracy against the recording and reread several times line by line before sorting and transferring the data into Nvivo 11 for the analysis.

Participants' mean age was 51.8 years with a post-qualification mean age of 23.2 years as GPs. These practices are integrated primary health care that served between 7,000-30,000 patients, which are typical of England.

Participants were sent the summary of analysis and requested to comment; the responses were positive and none of the participants discredited nor disbelief the comments or summary.

## RESULTS

After interviews with six GPs, saturation was reached as all the responses were similar around the

themes; a seventh interview was conducted, which was the same. The following themes emerged:

- Issues mitigating against the early diagnosis of AD;
- Recommendations for facilitating early diagnosis of AD in PC.

### *Issues militating against the early diagnosis of AD*

- In relation to issues militating against the early diagnosis of AD, six sub-themes emerged. These sub-themes include:
  - Ten minutes appointment time
  - Lack of continuity of care
  - High turnover of staff and resources
  - Lack of cooperation by patients
  - Lack of proactive and moderate knowledge by GPs
  - Issues of isolation in the aging population.

These subthemes are presented below individually.

### *Ten minutes consultation*

The ten minutes consultation time was seen by the GPs interviewed as a hindrance to identifying the early signs and symptoms of AD. This is mainly because in one consultation slot with the patient, the GP has to focus on one issue raised by the patient. This meant that the patient might need to visit their PC provider several times before the GP becomes aware that AD may be an underlying issue.

*Reference 3: Yeah, yeah, remember how the NHS works, a GP practitioner works ten minute appointments so I have ten minutes to see one patient for one problem, now so the way you diagnose is within the resources you have and a time limit you have; you might see the patient probably 6 or 7 times before you start thinking that this is a firm diagnosis of AD.*

### *Lack of continuity of care*

Other challenges included lack of continuity of care due to the current climate in the PC. The GPs related the high turnover of staff and the employment of the services of locums to the lack of continuity of care, as according to them, 'continuity of care brings a diagnosis'. Perhaps, recruiting more GPs or mental health nurses to undertake the screening of individuals and sustaining the continuity of care could enable the isolation of other presentations apart from memory loss.

*Reference 3: 'But often these days in general practice, you never see the same doctor, you must see a locum so patients don't get continuity of care and continuity of care gives a diagnosis. Where continuity of care practices is not the way many GPs would like it; it becomes so much of concern about their memory; it will exacerbate any anxiety.'*

#### *High turnover of staff and resources*

Participating GPs stressed that the high turnover of staff and limited diagnostic resources delayed their ability to engage fully with patients and negatively impacted on their ability to isolate the signs and symptoms early. The lack of resources meant that the issues of diversity in individuals, especially with language restrictions, were not considered in the early diagnosis of AD which may be a significant factor.

*Reference 1: There are other things in general practice now; you never see the same doctor you must see a locum company for the diagnosis.*

#### *Lack of cooperation by patient*

Still, on the issues that delay the early diagnosis of AD, participants reported the lack of cooperation by the patient themselves as a major issue.

*Reference 6: 'I think sometimes patients themselves try and normalize the concerns. I have patients who have frequently come to me and say well everyone gets forgetful a bit as they get older and also relatives.'*

#### *Lack of proactive and moderate knowledge by GPs*

Even though the participating GPs reported that they could successfully diagnose AD with memory complaints, they explained that the challenges are in part due to factors such as inadequate training of medical personnel towards the early diagnosis, as well as challenges of providing care for the patients after they are diagnosed with AD.

*Reference 4: 'That's the issue, in the NHS, where is the support? What do I do when I make this diagnosis? Is there a consultant out there who is there enough of them to say I can see them or support them, or to introduce any therapy?'*

#### *Issues of isolation in the aging population*

The issue of social isolation of the elderly was seen as a hindrance to early detection of AD. The isolation of this group makes it challenging for them to be assessed by the GPs, especially without a family

member that could bring the patients' attention to the GPs.

*Reference 6: 'I think people who are more socially isolated . . . may don't have family around or a lot of friends . . . they might not come to anybody else's attention because they manage somehow to function.'*

#### *Recommendations for facilitating early diagnosis of AD in PC*

Within the overall theme of the recommendations for facilitating early diagnosis of AD, participating GPs commented on A) availability of resources, B) services for the elderly, and C) enthusiasm for treating the elderly. These subthemes are discussed as follows:

##### *A) Availability of resources*

*Reference 3: We do have a very ethnically diverse population; we have a lot of southern Indians and people from Bangladesh, who are . . . certainly, have a higher risk of multi-infarct dementia. For some of those individuals again, the conventional testing isn't that friendly . . . so the six CIT test or the MMSE evaluation can be quite a challenge due to the language barrier.*

The extracts suggest that the NHS needs more human and material resources to help diagnose the disease earlier especially with a population that is racially diverse, such as is increasingly the case in the UK.

##### *B) Taking the services closer to the elderly*

The extract indicates the need to develop a system where those individuals who are 65 years and over are mentally assessed on an annual/regular basis possibly in their homes, as this was a strategy in other developed countries to isolate the disease and other chronic diseases early.

*Reference 1: Well, I think the main challenge is actually getting people to come to see us because a lot of people don't. So there isn't a mechanism in society at the moment to review people to get an assessment of their general health and their mental health. So in an ideal world, you have somebody who is dedicated to go and see every single person age 65 and over, once a year to do a mental health assessment and I mean everybody.*

##### *C) Enthusiasm for treating the elderly*

With regards to the treatment of the aging population, some of the participants noted that there was

a lack of enthusiasm from healthcare professionals in treating the elderly and that this was not the same when treating younger generations. The discrimination meant that their views were not treated equally as the younger generation.

*Reference 1: Well I think is very important, to me I think there is creeping ageism in our society and a lot of people now have very strong views about not treating people who get older with the same enthusiasm as you would treat young people; unless this is changed, we will continue to experience the same issues and even worse than what it is at present.*

## DISCUSSION

### Summary

This study is the first exploration of GPs' perceptions of early signs and symptoms of AD and examined issues surrounding the late diagnosis as well as recommendations against the delay in early diagnosis. The GPs interviewed have provided insights into the issues surrounding the early diagnosis of AD. The GPs being the primary care providers and the first point of contact for the patients serves as an important role in the early detection and the referral pathway for the diagnosis of the disease; the data present at the general practice enabled the identification issues surrounding the early identification of the signs and symptoms that might suggest screening strategies at the primary care to improve the prognosis of AD.

GPs characteristics play an important role in the diagnosis of AD, as confirmed by previous research [16]. Eligibility in this research, however, was based on their professional duties as GPs in the primary care setting; those who have had the responsibility of the diagnosis and management of AD patients within the last ten years, with responses similar around the themes. There was no distinction between the ages or gender of male or female participants, as the experience of managing AD individuals was the main inclusion criteria. Demographically, participants mean age was 51.7 years with a post qualification mean age of 23.2 years, which indicated that the GPs were qualified to comment on the issues, presented in this research and had the experience of managing AD.

The findings in this study identify the need for more professionals in the practice to support the limited current workforce as the participants mean age corroborates with recent findings that 54% of the GPs are above the age of 50 years with 82% likely to

quit or reduce clinical work within five years [17]. Also, 10% of the GP positions are unfilled and this situation shows no sign of changing [18]. This is an indication that the open positions need to be filled in, while the aging professionals, who are working extra hard to save our primary health care will subsequently require additional hands as they retired [19].

The gold standard for diagnosing AD is the 'Advanced Testing' [20, 21] which is currently unavailable in PC. It was acknowledged by the GPs that signs and symptoms, which are essential for the early diagnosis, are sometimes overlooked due to the current limitation on consultation times. Studies [22–24] have demonstrated the challenges with the current consultation time, which has interfered with the effective delivery of healthcare. A valid instrument might lead to early detection in the PC and fewer referrals to the memory clinic.

Furthermore, the funding crisis has seen the NHS employing the services of locums to sustain the services of doctors and plug the gaps created by a high turnover of staff. However, the use of locums in the NHS [25] has contributed to the lack of continuity of care, flouting the need for an integrated care approach for those in need of healthcare services. Additionally, the NHS spends nearly 25 times as much on locum agency fees as they spend on recruiting doctors to permanent positions [26]. If the reverse was the case, perhaps, there would be less of a service gap, with adequate continuity of care for patients, and a subsequent early detection of AD.

Central to our study is the finding that memory loss is considered the primary indicator to initiate a diagnosis of AD. The result is supportive of the literature [20, 27–29] where memory loss was identified as the early sign of the disease. However, other symptoms including apathy and odor deficits, have been identified, which are superior to memory loss in discriminating individuals at the early stage of the disease [30, 31] and use of the PC data has enabled us to identify others symptoms previously not investigated in AD [2]. This could help initiate patterns as a predictive model for early detection to be used in the PC.

Findings of our interviews with GPs also provided insights into the needs for professionals to be trained in this area and corroborated the findings of other researchers [32–35] calling for more training in the PC. This is to ensure that GPs can manage multiple comorbidities simultaneously and provide high-quality health care to meet the public expectations and the standards set by the Care Quality Commission.

The findings further demonstrate that the elderly population is not treated with the same enthusiasm as the younger generations by medical professionals. A recent report by [36] on medical professionals indicated a lack of sympathy by GPs toward the aged. Concern around this finding has led experts and policymakers to call for more training for medical students in geriatric medicine [37–39]. The call by the GPs for an annual check-up for those 65 years and above could also help diagnose AD earlier even though this could be impracticable in a system that is overstretched and likely not to withstand the analysis of evidence-based medicine. However, if the issues faced in the health care system are dealt with and a simple non-invasive predictive model developed, this could be practicable.

AD is a disease that was initially associated with ageism due to the high prevalence in the elderly population; however, it is known that the disease also affects the young, in a less frequent but often more dramatic way [40]; it is pertinent to provide patient-centered care irrespective of age.

#### *Strengths and limitation*

To the best of our knowledge, this is the first study that provides a summary of the perceptions of GPs regarding the constraints of ten minute consultation times, the inability to provide continuity of care and lack of training as the main contributors to late diagnosis of AD.

A limitation of the study is that the interviews were held with a relatively small group of GPs and that their views cannot necessarily be generalized. Although the responses from most of the participants were broadly similar, the restriction of participants to only two CCGs may reflect perspectives within a narrow geography rather than at national level.

#### **ACKNOWLEDGMENTS**

The Luton, Dunstable and Milton Keynes General Practise consortium helped with the data for this publication and includes Drs. Arnold Berger, Mokshad Kansagra, and Kulsoom Ali of Fishermead Medical Centre, Buckinghamshire, MK6 2ER; Dr. Manoj Sekharan of Milton Keynes Village Practice, Buckinghamshire, MK10 9BQ; Dr. Christiane Woloniecki of Woodland Avenue Practice, Bedfordshire, LU3 1RW; Dr. Emma Chakravarty of Leagrave Surgery, Bedfordshire, LU4 9QZ; and Dr. Anthea Robinson, Moakes Medical Centre, Bedfordshire, LU3 3SR.

The research received no specific grant from any funding agency in public, commercial or not for profit sectors.

#### **CONFLICT OF INTEREST**

The authors have no conflict of interest to report.

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