

**Title**

Explaining the Effects of Symptom Attribution by Carers on Help-seeking for Individuals Living with Dementia

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## Explaining the Effects of Symptom Attribution by Carers on Help-seeking for Individuals Living with Dementia

### **Abstract**

This study investigated the effects of carer attributions on help-seeking behaviour for people with dementia using interviews with 84 carers recruited through general practice.

Memory loss was the most commonly reported first symptom but psychological and behavioural symptoms were also common at onset. In over a third of individuals help-seeking was delayed for a mean of 25 months (range 6-69, SD 19.3). Help-seeking between those who attributed symptoms to dementia, or to unknown causes, and those who attributed symptoms to personality, ageing, life events or other illnesses was statistically significant ( $p < 0.001$ ). No statistically significant associations between help-seeking and patient or carer characteristics were found.

There is a need to raise public awareness about the range of symptoms suggestive of dementia. Assumptions that age and other conditions may be the likely cause of an individual's cognitive decline needs to be challenged by practitioners. Attribution of symptoms to characteristics other than dementia delays help seeking.

Key words: dementia • general practice • diagnosis • help seeking • carers • symptom attributions

## Introduction

Dementia currently affects 1 in 20 people over the age of 65 and in 1 in 5 over the age of 80 (Bunn et al 2012). Earlier diagnosis of dementia allows investigation of reversible causes of memory loss (Bradford et al 2009) and gives individuals and families time to organise personal affairs and plan a care package (Bunn et al 2012). However, a number of studies have revealed delays in the diagnosis of dementia (Iliffe et al. 1991, McCormick et al. 1994, Callahan et al. 1995, Vernooij-Dassen et al 2005, Bradford et al 2009). The National Dementia Strategy (2009) has highlighted a significant 'diagnosis gap' in England (DoH 2009), with only one-third to one-half of people with dementia receiving a formal diagnosis at that time (Chrisp et al 2011). A recent report by the Alzheimer's Society (2014) found variation in diagnosis rates within and between nations remains extreme, ranging from little more than a third in some areas to over 75% in others. One study in the UK reported a time from symptom onset to diagnosis of 3 years (Chrisp et al) whilst another noted a gap of 2.4 years between symptom onset and seeking help (Bradford et al 2009). General practitioners are blamed for this diagnostic delay. The All-Party Parliamentary Group's 2012 Report described general practitioners as *barriers* to early diagnosis (HMSO 2012).

Shigematsu demonstrated that in 85% of new diagnoses of dementia, memory loss had been the symptom that prompted help-seeking, although 63% of people with dementia also had other behavioural and psychological symptoms of dementia (BPSD) (Shigematsu 2011). Symptoms of dementia may not be recognised by the person living with dementia or the family, and some of the early characteristics such as memory loss, functional disability, or emotional lability may be thought of as 'normal' ageing (Pollitt 1995). Lack of insight can be a feature of dementia, so people may be unaware that they have a problem (Newens et al 1994) and resist seeking help. In addition, the stigma of dementia may prevent the person or family from seeking help because of embarrassment, shame, fear or uncertainty (Bunn et al 2012, Iliffe et al 2000). Symptoms can also fluctuate, complicating decision-making. For example, between 40 and 70% of people with mild cognitive impairment notice an improvement in their symptoms or are found not to have dementia (Le Couteur et al 2013, Mitchell & Shiri-Feshki 2009).

Age, education, employment, ethnicity and gender can influence help-seeking behaviour (Scheppers et al 2006). Older age, female gender and white race have been linked to a more proactive approach to help-seeking for mental health problems.(MacKenzie et al 2008) However, feelings of resignation, concerns about being perceived as 'weak' and low expectations of services also influence help-seeking behaviour in older people (Walters et al 2001). Health education messages are less persuasive for older adults and there is a

reluctance to want to appear ill due to ageing (Newens 1994). This reluctance may combine with wishes to 'not bother the doctor' and to preserve autonomy and identity, explaining why individuals and families may not pursue a diagnosis of dementia. Help-seeking may be further delayed when religious and cultural beliefs influence thinking about symptoms of dementia (Bunn et al 2012, Shigematsu 2011)).

Carers and family members are instrumental in seeking a diagnosis as they often recognise symptoms before the person affected. An earlier study found that 39% (n=104) of carers reported that they made contact with the GP when they first noticed that something was wrong (Downs et al 2006). However, the stigma of the diagnosis and the impression that little can be done for someone with a progressive neurodegenerative disease (Newens et al 1994) may often block the diagnostic pathway. For example, individuals and carers are more likely to seek help for mobility problems than for memory loss (Newens et al 1994). Both theory (Leventhal et al 1984) and empirical evidence (Hurt et al 2012) suggest that symptom attributions can be a cause of diagnostic delay. However, apart from a small qualitative study by Begum and colleagues (Begum et al 2012a) little research has been done about the attribution of dementia symptoms and its effect on help-seeking and consequently on diagnosis.

### **Aim of study**

This study is part of a larger study that tested the acceptance and effectiveness of tailored education in primary care in the identification, diagnosis and management of dementia (Wilcock et al 2013). The qualitative study reported here aimed to examine family carers' accounts of first onset and symptom attribution when they first became concerned about their relative's early signs of dementia. The aim was addressed through exploring the following questions:

1. When something was first noticed?
2. What were the symptoms at this time and what was the suspected cause?
3. How soon after first becoming concerned do families contact their primary care practitioner?
4. How do carers rate their experience of talking with the GP and the action taken at that time?
5. What rating do carers give to the way the GP responded to their concern about their relative and what influenced their rating?

6. What rating do carers give to the way the practice team as a whole responded and what influenced their rating?

## Methods

In 2010, 84 carers of people with dementia were recruited through their GP to take part in a retrospective survey of help-seeking behaviour in response to symptoms suggestive of dementia. The 19 practices from which they were recruited were participating in a randomised controlled trial designed to enhance dementia diagnosis and management skills in primary care (Wilcock et al 2013). The study took place in North London, Essex, Hertfordshire and Bedfordshire, UK.

People with dementia were identified by practice managers using the Quality and Outcomes Framework for dementia

(<http://bma.org.uk/practical-support-at-work/contracts/independent-contractors/qof-guidance>). The lead clinician for each person with dementia was asked to identify their carer and to give their opinion about the capacity of the person with dementia to give informed consent. Carers were defined as those who were responsible for either direct care provision for a relative or those involved in decision making with a relative still living independently. Those with poor command of English were excluded.

People with dementia judged as having decision making capacity (n=796) received a covering letter signed by their GP inviting them and their carer to participate in the study, a participant information sheet and a response letter and pre-paid envelope to be returned to the research team.

A researcher met those people with dementia and carers who expressed an interest in the study at the individual's home, in the practice or at the research team's offices to answer queries about the study and to gain consent from the carer and consent or assent from the person with dementia for their participation.

Two hundred and thirty eight carers were identified, 90 expressed an interest in the study, and 84 gave consent to participate and were interviewed. The process for obtaining participant informed consent or assent was carried out in accordance with the National Research Ethics Service (NRES) guidance

(<http://www.nres.npsa.nhs.uk/applications/guidance>), the Mental Capacity Act ([http://www.opsi.gov.uk/ACTS/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/ACTS/acts2005/ukpga_20050009_en_1)) and Good Clinical Practice (<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/index.htm>).

Carers were interviewed by one researcher (IT-B) experienced in interview techniques, using a semi-structured interview schedule developed by the same research team in a previous trial (Downs et al 2006). A semi-structured interview was chosen because this method is well established to be superior to other methods for eliciting good quality factual information (Cox et al 1981). However, to reduce the risk of context stripping by using only questions with pre-set answer options, free text answers were sought for answers of “other”, and for some questions where accessing the respondent’s definitions and interpretations seemed most relevant (Murphy et al 1998). Box 1 shows an example of the questions used in the interview, and their possible answers. The full interview schedule is available in the research programme report (Iliffe et al 2015) and from the corresponding author.

Box 1 Example of questions and answers

<b>Questions</b>	<b>Possible answers</b>
Can you tell me how long ago it was first noticed that something was wrong?	___months ago /Can't remember/Don't Know
Who noticed it?	Main Carer/ Other Relative/ Friend or Neighbour/ GP/Nurse/Social services/Other (who? – record details in free text) .....
What was it that was noticed?	Captured in free text
What did you think was causing it?	Dementia/ Age/ Other ...record details in free text
Was anyone at the practice contacted about it when you first noticed it?	Yes/No/ Can't remember/not applicable

If Yes to above, who contacted them?	Interviewee/ Other Relative/ Friend/ Neighbour/Don't know/ Not applicable
If No to above, How long was it after you noticed something was wrong before someone talked to the GP about it?	___months later/can't remember/ don't know/not applicable

The carers were interviewed in a place of their own choosing, usually their own home. The mean interview time was 98 minutes (range 30-205 minutes). The domains covered in the interview included diagnosis (e.g. symptoms that raised concern, attributions of those symptoms, speed of help-seeking, and time to diagnosis). Verbatim notes were made when participants commented on their reasons for delaying help-seeking. We opted not to audiotape interviews so as not to inhibit discussion around potentially sensitive subject areas.

Immediate help-seeking was defined as within 3 months of the onset of symptoms that caused concern to the individual, a family member or another. Answers were recorded on a proforma at the time of the interview. After the interview the structured coded responses to closed-ended questions were entered on SPSS version 20 software for analysis. Data were cleaned, discrepancies and implausible entries were checked against the paper questionnaire and corrected where necessary. Pearson's Chi-squared test was used where appropriate to assess statistical significance ( $p$ -value = < 0.05) and odds ratios were calculated for factors associated with immediate or delayed help-seeking.

## Results

### Demographic profile of participants

Three-quarters of the 84 carers interviewed were female (75%,  $n=63$ ). The average age of carers was 66 years (SD. 12.6, range 36-88) and the majority were married (86%,  $n=72$ ). Just under one half of carers were spouses (49%,  $n=41$ ), more than one-third of whom were wives (36%,  $n=30$ ). One third of carers were daughters (33%,  $n=28$ ), 11% were sons ( $n=9$ ) and 7% ( $n=6$ ) were other relatives or friends.

The majority described themselves as White UK (87%,  $n=73$ ), with 7% as White other ( $n=6$ ), 2% Black Caribbean and Black other ( $n=2$ ) and 4% Indian ( $n=3$ ). 61% were retired ( $n=51$ ), 11% were in full-time employment ( $n=9$ ), 14% in part-time employment ( $n=12$ ) with 14% being in the 'other' category, (i.e. homemaker, unable to work ( $n=12$ )). The mean age of leaving full-

time education was 17 years (SD 2.5, range 13-29), and more than half of carers interviewed had had further education (52%, n=44). The majority were home owners (94%, n=79).

Over one-third of people with dementia had a carer-reported diagnosis of Alzheimer's disease (35%, n=29), 17% of dementia (n=14), 12% of vascular dementia (n=10), 11% of mixed dementia (n=9), 5% of Dementia of Lewy-Body disease (4), 2% of Pick's disease (n=2) and in 19% the carer was uncertain about the diagnosis (n=16).

### **Symptoms and their attribution**

The interviewed carer had noticed the first symptoms of dementia in more than half of all cases (58%, n = 43). In one-quarter (26%, n = 22) of cases, symptoms were noticed by people other than the interviewed carer or the person aware of their own symptoms in 12% of cases (n = 10) and in only one case the GP was the first to notice symptoms of dementia. Over two thirds (69%, n = 58) of the interviewees reported noticing memory loss. More than half (55%, n = 46) also reported behavioural and psychological symptoms. Mobility problems were noted in seven cases, which included three people living with dementia who had fallen. Carers described multiple symptoms that made them suspicious in half of all cases (n = 42), whilst single symptoms were reported by just over a third (35%, n = 29).

More than a third of carers (39%, n = 33) thought that the symptoms that concerned them were attributable to a cause other than dementia (26%, n = 22) including cerebrovascular disease, stress, Parkinson's disease, brain injuries, bereavement, mobility problems and alcohol use. Surgery or the person's personality, diabetes, life events and tiredness were also suspected. A quarter attributed the symptoms to ageing (24%, n = 20) and a small proportion (12%, n=10) could not explain the symptoms.

### **Help-seeking**

Fifty one of the whole sample (61%) reported that they sought help within 3 months of the onset of symptoms that caused concern. Thirty three (39%) delayed help-seeking. Box 2 shows examples of how symptoms were interpreted in those who sought help immediately, and Box 3 shows accounts from carers who delayed help-seeking.

Box 2 Example symptoms described by carers in the immediate help-seeking group

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A friend notice that she was not playing Bridge as well as she usually did, her memory was not good. Her daughter didn't really notice but she was already under the mental health team for depression, so I alerted them [Sister reporting]

Mixed up his tablets. Things he was saying - repeating himself. Talking to dead wife. Asking if son is dead. [Daughter reporting]

Personality change, previously anxious now more relaxed. Went from phoning daughter regularly to only occasionally [Spouse reporting]

Box 3 Example symptoms described by carers in the delayed help-seeking group

She got lost driving to her daughter's house, and got very confused. The confusion – I didn't think it was serious [Sister reporting]

She was strange, said she had made the bed when she hadn't. Put the (electric) kettle on the gas cooker, didn't eat much and kept the same clothes on, and the lights. I thought it was just part of her personality. [Spouse reporting]

He let the salt grinder touch the food when using it. On holiday put suitcases down to look at map then walked off and left them. Poor co-ordination. As his memory was fine, I thought it was from heavy drinking, then thought he had had a TIA [Spouse reporting]

The rent wasn't being paid, she was not coping with other bills. I just thought it was part of mother's personality, she was always very direct and feisty [Daughter reporting]

If the carer thought dementia was the cause of the person's symptoms, they were nearly six times more likely to seek help immediately (see Table 1). If they thought ageing was responsible then they were significantly less likely to seek help. Carers who could not identify a specific cause for symptoms (12%, n = 10) were almost three times more likely to seek help immediately. If carers suspected another cause for the person's symptoms, other than the above, they were less likely to seek help (38%, n=32).

Table 1 near here

No significant differences were observed between immediate help-seeking and age of the person with dementia ( $p= 0.13$ ), gender of the person with dementia ( $p= 0.23$ ), carer gender ( $p= 0.90$ ), carer ethnicity ( $p= 0.65$ ) and ethnicity of the person with dementia ( $p= 0.31$ ). The educational level of the person with dementia ( $p= 0.35$ ) and carer ( $p= 0.17$ ) were also not statistically significant in influencing help-seeking behaviour.

### **Time to diagnosis**

Figure 1 shows the time from onset of symptoms to diagnosis. Carers could remember the time from symptom onset to diagnosis in 38 of 51 cases (74.5%) in the immediate help-seeking group and in 21 of 33 cases (64%) in the delayed help-seeking group. Recall was less complete for time from symptom onset to help-seeking in the delayed onset group, with 17 of 33 (51.5%) able to give a timeframe. Amongst those who contacted their GP soon after becoming aware of symptoms, the mean time to diagnosis was 16 months (range 0-48, SD 12.9), compared with 25 months for those who delayed help-seeking (range 6-69, SD 19.3). The delay in help-seeking in the latter group was 24 months on average (range 5-69 months, SD 19.3) but overall those who delayed help-seeking received a diagnosis 9 months later than the immediate help group. There were some delays between help-seeking and diagnosis in those who contacted their GP or other NHS services immediately. Box 4 shows examples of such delays.

Box 4 Examples of reasons for delays between GP consultation and diagnosis, in the immediate help-seeking group.

Referred to psychiatry but he didn't want to go- saw the Doctor again 2 years later, and he sent a psychiatrist to our house [Spouse reporting]

Referred twice, a two-three year gap between referrals, twice they (hospital specialists) said nothing was wrong [Spouse reporting]

Nothing happened initially but his daughter insisted he went back and asked for husband to be referred to memory clinic [Spouse reporting]

## **Discussion**

### **What this study shows**

In this sample, memory loss was the most commonly reported symptom that caused concern, either in isolation or accompanied by other symptoms, but behavioural and psychological symptoms were prominent at onset. In nearly two thirds of cases help was sought within 3 months of symptoms causing concern. More than a third of interviewed carers thought causes other than dementia were responsible for their family member's symptoms. Attribution of symptoms to other causes led to delayed help-seeking, whilst attribution to dementia was significantly associated with earlier help-seeking. These findings support Leventhal et al's (1984) Self-Regulations Theory which states that illness identity (i.e. attribution/making sense of symptoms) guides coping (help-seeking behaviours among other activities).

Those who had sought help when symptoms were first noticed received a diagnosis 16 months later whilst those who delayed seeking help (for 25 months) waited a further 9 months on average to receive a diagnosis, suggesting that the referral process may have been faster for those who did not seek help immediately. The reasons for this are likely multi-factorial and complex. Delaying help-seeking may lead to presentation with more severe and clear symptoms whereas earlier presentation can lead to delayed diagnosis in those who contacted their GP or other NHS services immediately. This is most likely caused by a combination of clinical, practical and psychosocial factors which require further investigation.

### **Strengths and limitations**

This is one of the few studies examining the effect of symptom attribution on help-seeking behaviour by carers of people who develop dementia. The strengths of this study are that it employed in-depth interviewing carried out by a single interviewer with a standard schedule developed and refined from a previous trial. Its limitations are that it involved a self-selected group of relatively affluent, educated White carers and findings were based on carer recall, which may have been prone to bias. Some carers may have ignored their relative's symptoms, a response which we were unlikely to identify in retrospective interviews. We were not able to assess whether the severity of symptoms influenced help-seeking, as some studies suggest (Bradford et al 2009).

### **Comparison with other studies**

Family carers can recognise symptoms, including memory loss and associated cognitive and psychological dysfunction as pathological (Newness et al 1994) but in this sample attribution mediated help-seeking, supporting Begum and colleagues' emphasis on 'causation' of symptoms as a factor influencing help-seeking (Begum et al 2012b), and Hurt and colleagues' views on the importance of beliefs about memory (Hurt et al 2012). A vignette study found that cognitive deficits are more readily identified as dementia than non-cognitive symptoms, which were commonly attributed to depression or stress (Hamilton-West 2010). In Clare and colleagues' study two thirds of people with early stage dementia referred to their difficulties as 'memory problems', and attributed their symptoms to ageing, sometimes also citing stressful or tiring jobs, falls or accidents (Clare et al 2006).

A recent survey by the Alzheimer's Society showed that more than 40% of people affected by dementia have kept concerns about the condition to themselves, and half of respondents had waited for six months or more after first noticing symptoms (Alzheimer's Society 2014). A recent YouGov survey suggested that help was not sought out of embarrassment, for fear of making a fuss, or because dementia was suspected (Alzheimer's Society 2014). Attitudes towards mental health are strong predictors of help-seeking behaviour (Helmes et al 2010).

The characteristics of the person living with dementia and their carers did not seem to influence help-seeking, contrary to other reported studies (Cattel et al 2000, Bradford et al 2009). Mobility problems were less influential in prompting help-seeking compared to other reports (Newens et al 1994). The majority of those who sought help immediately did so from their GP. Recognising the presenting symptoms can have an impact on timely diagnosis (Singh et al 2013) but GPs struggle to differentiate psychological disorders, including depression, from dementia (van Hout et al 2007), and lack of diagnostic confidence in primary care may further delay diagnosis (Iliffe et al 2006).

### **Implications for research and practice**

This study highlights the need to raise public awareness about the range of symptoms suggestive of dementia, and reinforces the conclusions reached by Hurt and colleagues (2012). Assumptions that age and other conditions may be the likely cause of an individual's cognitive decline may need to be challenged by practitioners.

Further research exploring the emerging themes on a larger sample size would allow refinement and appropriateness of recommendations for public and professional awareness campaigns around symptom attribution and earlier help seeking. This study did not set out to

explore the psychological processes of attribution or attitudes to help seeking and dementia in this age group which would be a worthwhile follow on study.

### **Conclusions**

Attribution of symptoms suggesting dementia to characteristics like ageing, life events or prior personality can delay help-seeking. In this sample suspicion of dementia, or uncertainty about the cause of symptoms, fostered help-seeking.

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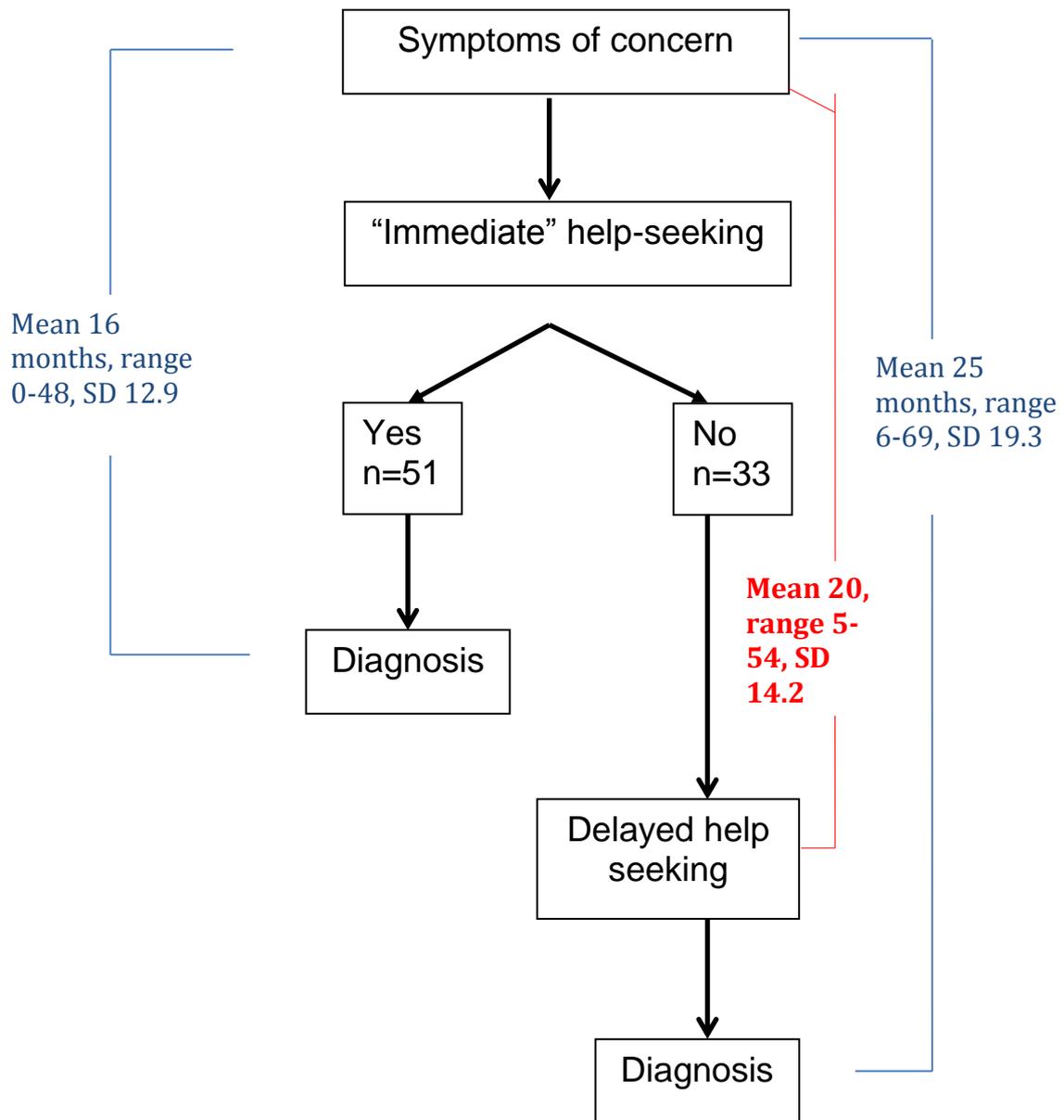
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**Table 1 Odds of immediate help-seeking, by attribution group**

	Seeks	Medical	Advice	Immediately	
Attribution	<i>n</i>	%	Odds Ratio	95% C.I.	P value
<b>Dementia</b> <i>n</i> = 22	19	86.4	5.937	1.593-22.129	0.008
<b>Unknown</b> <i>n</i> = 10	8	80	2.884	0.572-14.526	0.2
<b>Other</b> <i>n</i> = 32	18	56.2	0.74	0.302-1.817	0.5
<b>Age</b> <i>n</i> = 20	6	30	0.181	0.06-0.542	0.002

**Figure 1 Time from symptom onset to diagnosis in immediate and delayed help-seeking**



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