Help-seeking Response to Subjective Memory Complaints in Older Adults: Toward a Conceptual Model

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Purpose: Subjective memory complaint is a term used to refer older adults who report memory problems. Extensive literature exists on its etiology and impact on long-term cognitive decline, and some physicians consider it important in the early detection of dementia. Despite the salient features reported by both patients and clinicians, few people seek formal help for this complaint, and little research has investigated the underlying reasons for this. The current study explored beliefs, attitudes, and help-seeking behaviors. Design and Methods: A qualitative study was carried out comprising of 18 face-to-face in-depth interviews. The primary aim was to compare and contrast experiences between people, who sought formal help (n = 9), recruited from a memory service and those who did not seek formal help (n = 9) recruited from a screened community population. Results: The need for both to describe the experiences of an unexplored group and to develop a conceptual help-seeking model prompted the use of thematic framework analysis. Three themes were identified as facilitators and barriers to formal health service use: (a) concern, (b) causation, and (c) perceptions of general practitioner. We identified two further key areas central to shaping help-seeking responses: (a) informal help seeking and (b) alternative pathways to care. Implications: These findings suggest that there is a potential for modifying beliefs and attitudes towards help seeking and can inform the development of services and policy to facilitate help seeking and target and provide improved care or treatment when formal help is sought.

Key Words: Primary care, Qualitative methods

The Importance of Early Recognition of Cognitive Decline

Early recognition of and intervention for cognitive decline and dementia are considered desirable for people and their families, the value of which is multifaceted as recently reviewed (Prince, Bryce, & Ferri, 2011). Specifically, a diagnosis such as mild cognitive impairment (MCI) or early dementia of the Alzheimer type (AD) is necessary to access evidence-based treatment, care, and support. Receiving a diagnosis of MCI or early AD can result in reassurance and empowerment when people with dementia and their families are well prepared and supported through initial feelings of shock, anger, and grief. Earlier diagnosis allows people with dementia to plan ahead while they still have the capacity to make important decisions about their future care. They and their families can receive timely practical information, advice and support, and drug and nondrug therapies, which may
improve their cognition and enhance their quality of life. Early therapeutic interventions may also be more effective when started earlier in the disease course, for example to improve cognitive function, treat depression, improve caregiver mood, and delay institutionalization. On this subject, the latest World Alzheimer Report concludes “It is simply not true that there is no point in early diagnosis” or that “nothing can be done” (Prince et al., 2011).

Subjective Memory Complaints as an Early Symptom of Cognitive Decline

Despite the potential benefits of early detection of cognitive decline, little attention was paid on how people make decisions to present with early stage symptoms. There is no routine screening for cognitive impairment or decline in most countries, either in primary or secondary care. Subjective memory complaints are viewed by some as an early indicator of cognitive decline or dementia and form one of the standard criteria for the diagnosis of MCI (Ritchie, Artero, & Touchon, 2001), but it should be noted that subjective memory complaints are not sufficient to determine such a diagnosis. Some researchers have suggested that memory complaints may reflect mood disturbance more and their validity remains controversial (Jonker, Geerlings, & Schmand, 2000; Reid & Maclullich, 2006). A 3-year follow-up study investigating people who sought help for memory complaints found that their conversion rate to MCI or dementia was small and was more likely associated with psychosocial factors such as stress and anxiety (Elfgren, Gustafson, Vestberg, & Passant, 2010). The authors discussed memory complaints as a symptom of the “worried well”—a term often used to describe patients who complain of symptoms but often do not have any identifiable underlying organic pathology. However, the study focused on younger adults (<75) and there may well be a difference between cognitive complaints in younger and older adults. Furthermore, the follow-up period was limited to 3 years, which, for further decline, may be insufficient time in a sample with younger adults to become evident.

Help-seeking Responses to Subjective Memory Complaints

Despite the controversy surrounding the meaning of memory complaints as a symptom cluster, it is reasonable to suppose that at least some people with dementia will notice and admit to memory difficulties. How older adults themselves view these complaints on the whole is yet to be fully understood and is likely to be crucial for understanding help-seeking responses. With growing research interest in exploring the subjective experiences of people with dementia and how people with this disorder appraise their situation and conceptualize their lives (Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011), this is a question of increasing importance. We identified and investigated only five studies where factors with help seeking for subjective memory complaints are specifically associated. Two community surveys found the prevalence of formal help seeking to be 23% and 26%, respectively (Jorm et al., 2004; Waldorff & Rishoj, 2008). In the second study, increased number of General Practitioner (GP) visits in the preceding 6 months was found significantly associated with formal help seeking (Jorm et al.). Two other studies compared formal help seeking between samples drawn from memory clinics and controls from community and found that those who sought help were more likely to be worried about a family history of dementia (Ramakers et al., 2009). In the fifth study, beliefs about causation were the key features that distinguish between those who were seeking help and those who were not, along with those who made a pathological causal attribution being more likely to seek help and those who had a close relative with dementia (Hurt, Burns, Brown, & Barrowclough, 2011). This suggests that people who may view these symptoms as part of the normal aging process may be less likely to seek formal help. These studies used quantitative methodologies and, thus, were limited to epidemiological findings. The only qualitative study identified (Werner, 2004) has reported themes relating to causation: For example, some people thought memory decline was a natural aging process and, therefore, minimized the complaint, although they still reported memory lapses to be stigmatizing and embarrassing. Principal perceived barriers to help seeking were the cost of the formal assessment (the study being conducted in Israel) and the lack of treatment availability. This study, however, used a convenience sample of people who had memory complaints, none of whom actually sought formal help (Werner, 2004).
Potential Pathways to Care/Assessment in the U.K. Context

In the United Kingdom, the most common route to memory assessment services is via a GP (Iliffe & Pealing, 2010) for which there is no charge. The primary role of a GP is to provide an initial point of contact for all health problems that are not medically urgent. The structure of the health care service is based around the fact that GP acts as a “gate keeper” to secondary care services. Most U.K. memory services do not have open access, so most referral pathways are routed through GPs.

Conceptual Models of Pathways to Care

A large number of social science literatures have explored patient interactions with health care systems. The ways in which individuals and significant number of others perceive, evaluate, and act upon the symptoms of illness are encompassed within what is often referred to as illness behavior (Mechanic, 1968). Many of the studies described earlier did not use existing frameworks. The single qualitative study described earlier did not use existing frameworks. Often, qualitative research is underpinned by such conceptual frameworks, and researchers may try to develop conceptual models of decision-making processes (Doherty-King & Bowers, 2011). On the basis of his early work, Mechanic (1968) identified key factors that are known to influence illness behavior, including the nature of symptoms, influence of cultural beliefs, impact on family and social functioning, response of significant others, and the availability of health services. The main emphasis was that responses to illness or symptoms do not occur in a social or cultural vacuum, and the role of others is particularly important. The Health Care System proposed by Kleinman (1980) adopted and developed these ideas further. Its broad outline is shared with others within medical anthropology, in which responses to illness are viewed as the outcome of a complex interplay between social, cultural, and individual and health service factors. The key emphasis is that culturally shared beliefs about illness and treatments as well as the nature and configuration of the health service shape the interpretation of symptoms and what kind of help is being sought. According to this framework, the structure of health care systems is based on three sectors: the popular (self-medication and using help from kith and kin), the professional (medical professionals and/or formal institutions), and the folk (traditional healers). These sectors may overlap. Explanatory models are a key element: Namely, the individuals’ beliefs about illness inform the explanatory models of their specific illness episodes and exist for all those involved in the clinical process. Kleinman further argued that the interaction between the explanatory models of patients and practitioners is a central component of health care.

Study Background and Objectives

This article describes a qualitative study nested within a larger community survey (n = 124). Key findings emerged from this host survey were that memory complaints were common (66% of the sample) and viewed as concerning by some (30.4%), which, compared with other complaints (out of 15 alternative common complaints), were associated with lowest professional help seeking (Begum, Morgan, Chiu, Tylee, & Stewart, 2011). These findings informed the qualitative study design and reinforced the need to investigate underlying help-seeking behavior. The primary objective was to explore the reasons as to why some participants did not report their memory complaints to GPs while others did. In addition, we sought to explore participants’ general attitudes, beliefs, and help-seeking responses. Using Kleinman’s framework to aid data collection, analysis, and interpretation of findings, we present a conceptual model.

Methods

Eighteen participants were purposively selected, all of whom were residents of southeast London, United Kingdom. Nine participants who, on a structured questionnaire, had memory complaints and were concerned, but had not sought formal help, were selected from a community survey (non-formal help seekers [NFHSs]), full details of which are reported elsewhere (Begum et al., 2011). The remaining nine participants were recruited from a local specialist memory assessment service, the formal help seekers (FHSs) (Banerjee et al., 2007), on the basis of having originally reported memory complaints.
complaints to their GPs and having received an assessment from the memory service in the prior 6 months (See Figure 1).

**Data Collection**

The interview topic guide was designed to focus participants on three general areas of particular relevance to help seeking: (a) the nature of experienced memory problems, (b) the level of concern associated with complaints, and (c) the reasons for seeking or not seeking formal help.

In addition, we incorporated the eight questions suggested by Kleinman (1980) for eliciting explanatory models (See Supplementary Material).

Interviews were carried out in the participants’ homes and were recorded and transcribed verbatim. The majority of interviews were conducted with the participants alone, but the wife of one participant was present and provided relevant information at one instance (FHS 4). Interviews ranged from 30 to 90 min, each being reflected on by the lead researcher and discussed with supervisors before commencing the next interview, using notes during and after each interview to further aid the interpretative process. This process continued through the data collection phase so that thematic saturation could be determined. It was agreed that when common themes begin to repeat, interviewing was stopped.

**Data Analysis**

Thematic framework analysis was used to examine the interview transcripts (Bryman & Burgess, 1993; Pope, Ziebland, & Mays, 2000), following a process of detailed reading, annotation, and categorizing of interview transcripts to identify themes relating to the key areas of help seeking. Open coding was initially carried out to generate thematic categories rooted in the data. The development of a provisional coding framework was followed by the development of more abstract categories based on the observed relationships between the codes and the existing theory. The analysis was aided by the use of NVivo software.

**Stage one: Thematic analysis.** – This included the “familiarization” and “indexing” stages of a thematic framework analysis (Green & Thorogood, 2004). The formal coding was carried out by three coanalysts (A. B., C. M., and K. S.) after the data collection was complete. Two of them were not involved during the data collection phase. The third analyst was the lead researcher who carried out the interviews. Descriptions of codes were first formally developed inductively from two randomly selected transcripts: one from the nine of the formal help-seeking group and the other from the nine of the nonformal help-seeking group. Thematic analyses were

![Figure 1. Sample recruitment process.](image)

#Concern scale: 1 = not at all concerned, 5 = very concerned. Five people had no concern score.

*We contacted people one by one as each interview was completed. Interviewing was stopped when saturation was met, irrespective of the number of people left to contact.

**Three-fifths of people who refused had dementia and 2/5 were reported by caretakers as being made very anxious by interviews regarding memory.
applied independently to both the transcripts. Three-way meetings were held to discuss codes or themes that had emerged. Discrepancies were discussed and the process was completed when consensus was agreed. The level of discrepancy was not recorded. However, discussion about these continued until all three analysts were in agreement (Phase 1). The initial coding framework was then applied to a further random selection of two transcripts from each group (Phase 2), carried out by A. B. and C. M. A free code was established so that uncertain sections of the transcript could be discussed. The final phase of the analysis was carried out by A. B., where all remaining transcripts were analyzed using the latest coding framework. This process of multiple coding and teamwork was adopted to minimize subjective bias (Armstrong, Gosling, Weinman, & Marteau, 1997; Barbour, 2001; Mays & Pope, 1995).

Stage two: Further analysis. — The primary aim here was to investigate differences in thematic patterns between the two groups. Thematic framework analysis was chosen specifically because the “charting” and “mapping and interpretation” stages allowed us to do this (Green & Thorogood). Moving on from a basic thematic analysis, “charting” allowed us to compare both within and between the cases, and “mapping and interpretation” stages enabled us to look for relationships between the themes (Green & Thorogood).

Ethical approval was obtained from the joint South London and Maudsley and Institute of Psychiatry NHS Research Ethics Committee. After complete explanation of the study, all participants gave written informed consent.

Results

Eighteen participants were interviewed. Table 1 summarizes key relevant characteristics. The median age of the FHSs and NFHSs was 78 and 74, respectively. There were eight women in the FHS group and five in the NFHS group. There appeared to be little difference in their educational attainment. All of the FHSs were categorized within the top three social class groups. The NFHSs, however, belonged to a wider range, and none of them were in the highest social class group.

All participants had a formal assessment of their cognitive function. Only one participant, who was in the formal help-seeking group, had a diagnosis of dementia—in his case, the dementia was in the context of Parkinson’s disease. The remaining eight formal help seekers had MMSE scores in the conventional “nonimpaired” range, and none had received a diagnosis for dementia from the memory clinic after seeking help. Amongst the NFHSs, two participants’ MMSE scores were within the impaired range. Cognitive impairment is often associated with increased age, and given the minimal difference between the two groups in both age and cognitive status in our sample, it was not felt that these factors affected help seeking. We also investigated related themes, such as severity of complaints, and this also did not appear to be a discriminating feature between the two groups.

Three key themes emerged that appeared central to formal help seeking for memory complaints and two further key areas appeared central to shaping responses. These were (a) extent of concern, (b) causal beliefs, (c) perceptions of GP role, (d) informal help, and (e) alternative pathways to care.

<table>
<thead>
<tr>
<th></th>
<th>Formal help seekers (N = 9)</th>
<th>Nonformal help seekers (N = 9)</th>
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<tr>
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<td>74</td>
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<tr>
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<td>5</td>
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<tr>
<td>Highest qualification, N*</td>
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<td>4</td>
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<tr>
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<tr>
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<td>(Registrar General’s classification)</td>
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<td>III Skilled nonmanual</td>
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<tr>
<td>III Skilled manual</td>
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<td>1</td>
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<td>IV Semiskilled manual</td>
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<td>V Unskilled-manual</td>
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<td>2</td>
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<tr>
<td>Participant 9</td>
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<td>30</td>
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</table>

Note: *Person with dementia (PD) and Social class and qualification missing.
Concern

The extent of concern was the most prominent distinguishing feature between the two groups when participants were directly asked why they did or did not seek formal help. Seven formal help seekers talked explicitly of feeling worried or concerned, but the two remaining people who might have felt that way did not mention this. One person had regularly read articles to find out about future treatment advances: “No, no, I’d been worried about it for a long time but—that was just an article that said that; there were tablets out now that they could give you to delay the onset of it” [FHS 1].

Others also described their experiences, within the context of their worries and concern.

Well, I’m concerned enough to contact you, you know, make contact with you people, but I can’t go through my life worrying—I was the one that people came to for things; I’m not the one that asks people for things, if you know what I mean; I’m always the one that’s got the answer and I haven’t now—I suppose this is what makes me worry about it. [FHS 2]

One participant described how she continued on feeling concerned about her memory problems, despite undergoing a formal assessment that confirmed that her memory problems were not getting worse.

... I went back to my doctor and I said to him, you know, can I go back and see the lady—and the lady came here and we, um—these tests, you know where she showed me the pictures, and she went through the numbers and what have you, and she said the tests were the same as the first time, so there was nothing to worry about, but to me those tests—I can’t sort of explain it. I know that things have got worse, I know, I know myself things have got worse, so you telling, not you particularly, but you telling me that I’m the same as I was last time, that doesn’t wash, you know. [FHS 5]

For some people, this concern was so strong that the fear of developing dementia was expressed powerfully during the interview. One participant described how she would rather have cancer than dementia.

... Well, I think it’s one of the worst things that you could suffer from; you don’t die of it, unfortunately. I’d much rather have some physical thing, cancer or anything else than that; it’s like a living hell—because you’re not in control of your mind, you know, you’re not you, you haven’t got an identity, have you ... [FHS 8]

Conversely when the NFHSs were asked about why they didn’t see their GP, four participants specifically said that they were not worried or concerned about it. This person described how having some lapses in memory was, for him, not particularly concerning.

... It’s never bothered me much; I accepted it like I had a sort of—a bad memory, you know, and it didn’t sort of worry me ... I feel that I—I’m managing you know, er—and I think I’m doing quite well in my own mind; um, if I forget a few things the world isn’t going to collapse, you know. [NFHS 4]

Causal Beliefs (Explanatory Models)

Both groups reported a range of causal beliefs for how they interpreted their complaints, from biomedical (e.g., familial risk) to psychosocial (e.g., work related stress). There were accounts in which the concern mentioned earlier was associated specifically with the perceptions of familial risk of dementia. A pattern to emerge was that, of the six NFHSs who explicitly stated a causal attribution in their interview, four attributed more psycho-social causes, citing reasons such as anxiety or stress, depression, poor sleep, and consumption of too much alcohol. One person reported feeling depressed after the death of his wife and thought this was making his memory problems worse, stating “I think it’s even got more so, since my wife died” [NFHS 4].

Another person described how introducing someone at a function induced anxiety about remembering names and how this increased her memory lapses: “I think it comes also with anxiety; oh, am I going to remember in a party? You know, you have to introduce someone” [NFHS 2]. Of the two remaining people, one reported “natural deterioration,” and the other cited familial risk.

On the other hand, the FHSs more often gave accounts involving biomedical explanations. Seven people explicitly stated causal beliefs. Four cited biomedical reasons, three of whom explicitly mentioned familial risk, and the other referred to her surgery or stroke. Two people described “natural aging,” and the remaining person attributed the complaint to “stress or too many demands.” Participants in this group were often troubled by experiences of a close family member who had dementia and, where this was the case, it remained a key focus of their interview. An example of this was a participant who,
throughout the interview, clearly stated that she sought formal help because her grandmother had dementia. “Well I sort of think if she had it, and she was my grandmother, will I have it like, you know?” [FHS 1] This theme was also common in other accounts.

Well, only the fact, as I say, that I remember my grandmother, and I realize that, well, nothing could stop me getting like her and I, I sort of keep on trying to console myself... [FHS 2]

Perceptions of Health Systems: Providers and Services or Treatments

Overall, positive views about health systems were reported more frequently by the FHSs. Eight of the NFHSs explicitly commented on health systems when directly asked why they did not or would not seek help. All of these commented specifically on the GP and the GP’s potential response, with all commenting on more than one aspect of this. There were a range of examples. In general, there was a view that GPs should be consulted for more biological or physical symptoms such as localized pain or something serious. Seven participants expressed some notion of this. More specifically, however, there was a desire not to waste a physician’s time, a strong sense of feeling that a GP would be very busy and should not be “bothered” or “pestered” unless something serious came up: “I suppose wasting other people’s time, particularly a doctor; you know, doctor’s busy.” [NFHS 1]. Another participant commented: “That’s something—you know, I don’t want to pester him...” [NFHS 6]. Four people explicitly gave accounts relating to this. Another commented: “Well they are overworked as it is, and you know—that you need to go if there’s something seriously the matter not if it’s an insignificant worry” [NFHS 8]. It is possible that this comment may reflect severity, which overlaps with the general view about when to see a GP. However, it was stated in the context of the GP being over worked, possibly suggesting a desire not to bother him or her.

In addition to the GP being perceived as too busy, three people expressed concerns that the GP may not take the complaints seriously or be concerned: “I don’t know whether I feel that a GP would be so concerned.” [NFHS 9]. Another commented: “I don’t like going up there you know, and I don’t want to tell them because—they don’t bother—like once you’ve reached the age of 70, you’re a number” [NFHS 6].

Six people commented that they felt a GP could not help, meaning there was no cure, and in particular, two people had some concerns that a GP may just hand out medication for cognitive impairment, which, in some cases, was perceived as not being effective. One participant commented, “Well at, at this stage there’s nothing they can do anyway” [NFHS 8]. Another said:

What can he do, prescribe drugs for me? That’s the last thing I want—busy GP—just give you a few pills and get rid of you, and then you’ll go even more gaga. So no, I wouldn’t even think of it. [NFHS 1]

Two men also reported pride as being a barrier, suggesting that presenting to a GP may hold some stigma.

It’s self image, that, erm, it’s corny, really—I’m a man. I would like to be seen as, erm, well, being able to look after myself, I suppose, unless it’s a crucial thing—but to come in, you know crying over a sore finger or something... It’s just—yes, I would not like him to think I’m a wimp, I suppose. It’s just petty pride. [NFHS 1]

Informal Help Seeking: (Family/Friends and Self-help/Coping)

Every participant had described instances of informal help seeking. This included speaking to friends and family and adopting self-help strategies. For some, needs for help and support were met by disclosure to friends and family and general lay encounters. One person described how talking to other people was helpful where they had similar experiences: “We talk to each other because we’re all more or less in the same boat” [NFHS 2]. Another person described how talking to people with similar complaints made her less likely to “bother” (i.e., worry) or seek formal help.

... I suppose to people like—odd people who you know—you sit on the bus, you talk to people, or you sit in the—I’ll go down to the Cutty Sark—I’ll sit on a bench and people just come and sit next to me; we talk, you know, and then they say to me oh, I went to the shop, and they forget something. I said the same has happened to me, so I said, oh thank God, I said, I thought I was the only one. They said, no, it’s when you get old your brain don’t work so fast and they say—they tell me, and it sinks in, and I bet they must be right; that’s why I don’t bother. [NFHS 6]

Some people preferred to cope by themselves. At times, this seemed to be in response to perceived
lack of treatment. One participant, for example, said that he preferred to cope on his own but also said that the GP may not be able to help anyway.

I didn’t know there was any help that a GP could offer you. I keep away from my GP as much as possible—I like to cope by myself, on my own, as much as possible. [NFHS 3]

There were, however, accounts of self help accompanied by examples of specific coping strategies. These often appeared to be actual alternatives to formal help seeking and could be viewed as “active self-help.” Active self-help seemed to fall into two main categories: Those who used alternative homeopathic remedies (i.e., alternatives to medication) and those who used strategies such as brain exercises, reading, crosswords, and physical exercise. Another participant described his preference for homeopathic remedies and thought that the medication prescribed by the GP would make his symptoms worse.

I’m taking things like cod liver oil and various tablets to see if that helps a bit, not drugs—people say you should take … folic acid, is supposed to be good for your memory … so occasionally take those. [NFHS 1]

Another participant described keeping mentally and physically active: “Your brain doesn’t work so hard … so I try to do … crosswords, and word search, you know, and I like music and, you know, I keep myself active, I go for walks, you know” [NFHS 6].

Alternative Pathways to Care

One characteristic of older adults is that they are more likely than younger adults to consult their GPs and be in contact with a range of health professionals for physical health problems (Lehnert et al., 2011; Parekh & Barton, 2010). This has two consequences: (a) medical surveillance—health professionals, in the process of addressing other complaints, may recognize memory problems and facilitate help seeking, and (b) opportunistic help seeking—individuals may use routine check-ups and consultations for other problems opportunistically to raise concerns about memory problems. There was evidence of both in this study.

… you spoke to [name1] in the Parkinson clinic at [local hospital1] and then you saw [name2] at [local hospital2] … [name1]—was the Parkinson’s sister in charge of the Parkinson’s clinic, at the health centre in [local hospital1], which he used to go every six months, and they used to test him and they were the ones that, err, prescribed his medication—once his memory started to get really bad in, in—on the trip round to the doctors for his check-up he mentioned it to Dr [name3] and he got us in touch with the memory service. [FHS 4: Participant’s wife]

Overlapping with being “visible” to health services, there was evidence of opportunistic help seeking. Some participants had sought help at 6 month follow-ups with their GP or primary care nurse as part of a review process for another medical problem. One participant, for example, described waiting until her routine check-up (for another disorder) was due and mentioned it to her GP later, despite being concerned about her memory for some time before, “I didn’t go down there; I just—he came to see me one day about something else, and I mentioned it to him—and he said, is it worrying you, and I said it is really” [FHS 1].

Although many FHSs took such alternative pathways when seeking help, some participants took more direct routes, independent of any existing contacts with health professionals. One participant, for example, described her realizing that something was not right immediately when she began to experience difficulty finding words and started to stutter, and it was this that prompted her to visit her GP.

Yeah, I mean every, every so often, not happening at the moment, but every so often I’m, I’m developing a stutter. I’ve never had a stutter in my life, you—um, it’s not bad, but I know it’s there, um. I went back to the GP because I suddenly, every so often developed this stutter, and I’m losing words which at the time—before I wasn’t losing words, it was just not being able to remember. [FHS 5]

Discussion

To our knowledge, this is the first in-depth exploration of why some older adults with memory complaints seek formal help and some do not, eliciting this information from a sample of FHSs and NFHSs. We have drawn two main conclusions.

First, we found evidence that older people gain access to assessment for memory complaints via a number of routes. Some participants had beliefs about causes that shared, in outline, many characteristics on the basis of a biomedical understanding of memory complaints. As such, we suggest a conceptual medical model of help seeking. In this empirically grounded model, we posit that people
more likely seek formal help view their complaints (a) as concerning, (b) as having a biomedical cause, and (c) without holding negative views about presenting to their GP. Kleinman (1980) suggested that movement between the popular and professional sectors within the health care system will be the easiest, where popular perceptions of disorder overlap with those dominant within the professional sector. Findings from our study support this framework. Those who broadly held biomedical beliefs about causation were more likely to seek professional help. However, this conceptual model is challenged by our additional findings on medical surveillance and opportunistic help seeking, which provided some evidence supporting alternative pathways. Figure 2 illustrates the factors that influenced pathways to formal and informal help seeking.

Our second conclusion is that despite having evidence of more than one help-seeking typology to the professional sector, not everyone entered this sector. Instead, some people remain within the popular sector and seek informal help. For many of those who did not engage with professional services, informal help seeking may have reduced the need to seek formal help. It is possible that the relative lack of concern reported by this group was, in part, the result of having their fears and concerns allayed by informal discussions within their social networks. It is also possible that people who viewed their complaints as part of a normal aging process received reinforcement in this view by sharing experiences with friends or family having similar complaints. However, despite these concerns or fears being allayed, not everyone’s memory lapses will have the same underlying pathology, and for some, further formal investigation may be appropriate.

The relationship between the level of concern and causal beliefs (explanatory models) may be circular and reinforcing. One possible reason for the lower level of concern expressed among the NFHSs was that some of these people’s causal beliefs for their complaints were of natural aging or psychosocial and, therefore, possibly were “normalized” to an extent (Vestergren & Nilsson, 2011; Werner, 2004). Biomedical explanations among the FHSs were often based on their experience of family or close relations having dementia, whereas for many of the NFHSs no such experiences were reported. This finding supports earlier studies where formal help seeking was significantly associated with people having a family member with dementia and concerns about a family history of dementia (Hurt et al., 2011; Ramakers et al., 2009), or a pathological causal attribution (Hurt et al., 2011). It is, however, necessary to bear in mind that people who have sought or received formal help may begin to “medicalize” their symptoms.

Figure 2. Various factors impact on the likelihood of formal and informal help seeking, each contributing to “funneling” individuals along one or other pathway.
The transformation of experiences into biomedical symptoms has received heavy criticism, particularly in psychiatry, and this issue should be considered in a study such as this, which operates on an assumption that better access to assessment within a biomedical framework is a beneficial outcome. However, much of the criticism has focused on clinics introduced to identify and treat psychosis at an early stage (Whitaker, 2010), where the large numbers of false positives in low risk groups may result in needless stigma, concern, and distress to individuals and their families as well as economic costs (Yung & McGorry, 1997). Medicalization of memory complaints might potentially have similar consequences and should be considered. However, one study found little evidence on the problem of false-positive cases in memory clinics (van Hout, Vernooij-Dassen, Jansen, & Stalman, 2006), and memory complaints are generally viewed with far less stigma than psychosis, although there is evidence to suggest that some older adults do report them as being embarrassing (Werner, 2004). Our study was not designed to assess the process through assessment and beyond or to generate evidence for or against the appropriateness of pro-active memory assessment services. Instead, it focused on the pathways leading up to assessment and sought to provide information that might underlie inequalities in access.

Our medical model suggests that a pathway to the professional sector is more easily facilitated if people do not perceive additional barriers to presenting. Overlapping with this concept are the findings in the earlier qualitative study by Werner (2004), where the Health Belief Model (Becker, 1974; Becker et al., 1978; Eraker et al., 1984) was used. In line with individual rational choice theories, the Health Belief Model begins with the viewpoint of the individual and views their position or role within the context of a wider social environment as less significant. The main limitation is that it is based entirely on the individual’s perceptions and fails to emphasize the importance of a social process. We found examples of people gaining entry to the professional sector via two alternative routes. Contact with professional services for other symptoms increased the opportunity for professionals to recognize memory problems and also allowed increased opportunistic help seeking for patients themselves, enabling formal help to be sought without the impact of perceived barriers. A study described earlier found that formal help seeking for memory complaints was associated with increased contact with GPs (Jorm et al., 2004). Opportunistic help seeking through the GP is not unusual and has been described in other areas (Getz, Sigurdsson, & Hetlevik, 2003; Stott & Davis, 1979). Being already visible in the medical system provides more opportunity to seek formal help or to be the object of medical surveillance and also provides a reporting opportunity for those who are less concerned about their memory.

A key aspect to these alternative pathways into formal care is comorbidity. People who are highly impaired may be more likely to have help-seeking decisions made on their behalf either by a spouse or by a health care professional. As such, the process becomes rooted in social networks, again theoretically supporting the Health Care System framework. One of the main strengths of this framework is its emphasis on the interconnectedness of all health-related components in society and on how health- and illness-related behaviors are socially and culturally shaped through the interaction of a wide range of factors in specific local settings. One participant with dementia and Parkinson’s disease, for example, though able to communicate his memory complaints during the interview, had limited capacity and was being cared by his wife, who also clarified and corroborated what the participant said during the interview. The referral to the memory service came about after tests were carried out by his nurse during a routine follow-up, and his wife then made arrangements with the memory service to assess him through their GP. Evidently, older people who are already “visible” to medical services may be more likely to receive medical referral and help as a consequence of health professionals intervening to suggest or promote help-seeking.

Even in the absence of comorbidity, decisions facilitating movement from the popular to the professional sector are likely to be embedded within the social network. We found evidence to support this, not only with the alternative pathways but with the negotiations that people had with others, which is evident in informal help seeking from friends and family. Lack of social support (Cameron, Leventhal, & Leventhal, 1993; Pescosolido & Boyer, 1999; Rickwood & Braithwaite, 1994) and physical limitations (Lee, Hasnain-Wynia, & Lau, 2011), therefore, become important influences on help seeking. Though these factors were not investigated directly, a process involving social networks is plausible that could provide alternative means for coming into formal health service other than the described pathway. Other factors that
were not specifically investigated in our study may also be influential. For example, we found that two men reported “pride” as a reason for not seeking help, and the FHSs were almost exclusively female participants so that it is possible that gender influences help seeking. Women may be more likely to seek help, both formal and informal, for health complaints. We also recognize that factors such as education and socioeconomic status, which often correlate with health literacy, may be potentially influential in formal help seeking. Both the groups had a similar level of educational attainment, but the formal help seekers were all categorized in the top three social class groups, whereas the NFHSs had three members falling within the lower three groups. Higher social classes may be more likely to seek formal help, but none of these additional issues were discussed in the interviews, and, therefore, firm conclusions cannot be drawn.

Clinical Contributions

Our findings highlight some potential barriers to people achieving assessment for memory complaints, particularly in relation to the perceptions of GPs. There may, therefore, be a need to address the negative views and stigma that some view in presenting to a GP, so that help seeking can be facilitated more easily. GP training on early diagnosis of dementia exists and is increasing in response to the greater priority accorded to dementia by initiatives such as the National Dementia Strategy for England. Such training needs to place emphasis on how a GP’s response to older patients at presentation may affect formal help seeking and how to overcome these barriers.

Public attitudes and understanding of dementia and memory problems are of importance. Health awareness and promotion campaigns could be used to modify beliefs and attitudes about memory complaints and help seeking by drawing attention to the following: (a) the importance of memory complaints and the different causal attributions, (b) how to self-evaluate for managing levels of concern, (c) how and when to seek help, and (d) what help and follow-up support can be expected.

Limitations

We acknowledge two main limitations. The specific use of thematic framework analysis was adopted to illustrate patterns of behavior between the two groups. However, in addition to help-seeking responses, there were differences between the groups that may have influenced the findings. For example, many of the FHSs had preexisting health conditions which may have given greater opportunity for the disclosure of memory complaints. We also did not exclude those with existing disorders affecting cognition. Finally, many also had close relatives who had dementia and all participants but one from this group were female. The second limitation is that the two groups were interviewed at different stages on their pathways to care, which may have influenced responses: particularly regarding perceptions of GPs and causal beliefs about the complaint. People who have received formal help may hold more positive views about health services because of this. We cannot necessarily infer what the FHSs thought about their GPs prior to seeking help. Also, a FHS’s recall of reasons for help seeking in the past may be influenced by the receipt of such help: for example, some people may “medicalize” their symptoms after receiving help, although anecdotally some participants who had received a memory service consultation remained dissatisfied with not having their complaints confirmed as pathological or “abnormal,” suggesting that this perception of causation may have been present before the intervention.

Given the limitations of this sample, larger studies could be useful so that participants can be selected purposefully for a greater number of variables such as age, gender, education or socioeconomic status, level of comorbidity or disability, level of social support, personal experience or history of dementia and cognitive status (paying particular attention to the presence of coexisting and potentially contributing disorders such as Parkinson’s disease and stroke in which people may have different interpretations of memory problems). Longitudinal studies could also confirm the underlying pathology of these complaints and therefore allow further inferences to be made about the “worried well” and help seeking. These studies could also capture help seeking over time, allowing the measurement of people’s experiences, attitudes, and behavior both before and after help seeking and in turn providing a more accurate account of explanatory models of memory complaint at each occasion. Investigating multiple help-seeking episodes could potentially allow the social processes of informal and formal help seeking to be more visible. Because formal help seeking includes physicians’ explanatory models (how a physician understands and treats illness), these could also be investigated.
Supplementary Material

Supplementary material can be found at: http://gerontologist.oxfordjournals.org.

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