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Patients' and carers' views on communication and information provision when undergoing assessments in memory services

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Abstract

Objectives: To explore patients' and carers' views on what constitutes high-quality communication and information provision during diagnostic assessment in memory clinic services in three areas of England.

Methods: Interviews with 27 people with cognitive impairment (13 with confirmed dementia) and 26 carers (20 matched pairs). Interviews continued until theoretical saturation was reached. Interview transcripts were subject to constant comparative analysis; data interpretation occurred in 'data clinics'.

Results: People with memory problems undergoing assessment often have unmet information needs, especially patients with a diagnosis other than Alzheimer's disease and those who do not receive a diagnosis. Patients wish to be kept informed about both the assessment and its outcomes. Some have unrealistic expectations of the process (expecting assessment and diagnosis to be complete in two weeks) and some experience what appear to be long delays (over 12 months) in receiving results. Most appreciated clear and honest communication about any diagnosis. Post-diagnostic groups, organized by local memory services, afford opportunities to learn practical strategies and gain informal peer support. Voluntary organizations may be an essential source of information.

Conclusions: Communication and information need improvement for patients undergoing assessment for possible dementia, especially for those considered unlikely to benefit from medication and those with mild cognitive impairment.

Keywords

communication, information, memory clinics

Introduction

Little is known about the experiences of people with memory problems who attend memory clinics, or those of their carers. Information provision and communication by professionals are reported as variable and not generally evidence-based.[1–3] Although a recent government information strategy in England emphasized the importance of information about

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health and social care,[4] it focused on macro-level systems rather than the detail of what constitutes high-quality information provision. Its aim to achieve more integrated information provision is welcome, but an over-reliance on electronic systems may be inappropriate for people with memory problems. Many countries are developing dementia strategies which highlight the importance of providing patients with information[5]; in England, the National Dementia Strategy has also piloted a Dementia Advisor service to facilitate information transfer.[5] Current consensus around the provision of information to people with dementia following a diagnosis recommends offering individually tailored information and support over time.[2,3] To date, evidence on the effectiveness of interventions that incorporate information provision reveal some benefits in quality of life for people with dementia but little effect on carer burden.[6]

Regarding the amount and volume of information people with dementia and their families want, studies demonstrate variable findings. Some carers wish to be given as much information as possible,[7,8] whilst some wish information to be staggered[9]; other studies reveal carer frustration at a lack of information at this important time.[10] Regarding the nature and type of information required, carers most commonly desire information around disease progression, what to expect in the future, and the availability of therapies and services.[11] However, research exploring what information people with dementia themselves want is very limited.[12] Our aim was to explore the views of patients and carers on what constitutes high-quality communication and information provision when undergoing assessment in memory clinics.

Methods

The perspective of constructionism underpinned our study design and methods. Constructionism suggests that each individual constructs his or her own perception of reality and that researchers subjectively reinterpret the accounts of study participants.[13,14]

We conducted interviews both with people with memory problems and with their main carers. Participants were recruited from four memory clinics: London, North West England and two in North East England. Patients were referred to them from GPs and the clinics had responsibility for the assessment and diagnosis of dementia. All had input from old age psychiatrists, mental health nurses and psychologists, and referred patients back to GPs following assessment and, if relevant, diagnosis. All clinics provided continuing input (ongoing review) for those prescribed anticholinesterase drugs for Alzheimer's disease.

Memory clinics were chosen as a recruitment source because they see people relatively early in the development of dementia.[15] People with dementia and their carers were recruited both retrospectively, a dementia diagnosis disclosed within the previous three months, and prospectively, participants attending a memory clinic for assessment who had not yet received a diagnosis. The latter group was interviewed about their experiences before and after diagnostic assessment, whether or not a diagnosis was made. The patient and their carer were mostly interviewed together. Only people who were able to consent to participate in the research were included; assessment of a participant's capacity to make the decision to participate was determined by the completion of a short pro forma.[3]

Data collection took place between September 2009 and March 2010. Purposive sampling guided the selection of participants; the initial sampling frame was expanded to recruit more women and a wider variation in socioeconomic status.[16] All interviews took place in participants' homes, using an interview topic guide that drew on the literature to explore the assessment processes and diagnosis disclosure,[17] possible experiences of being prescribed medication for symptoms of dementia[18,19] and risk and decision-making.[20] Interview summaries were sent to each participant; follow-up telephone calls corroborated the issues. This was an opportunity for summaries to be amended according to participant feedback. All participants were satisfied that the main issues were recorded in the summaries and so no changes were made. Researchers also wrote regular reflexive diaries that served as field notes. All interviews were digitally recorded and transcribed. An identification number was created for each participant with the letters indicating whether the participant was a person with memory problems (P) or a carer (C). Anonymized transcripts were shared amongst the research team for purposes of data coding and analysis.

Recruitment ceased when no new themes were identifiable. This decision was made by the analysis team in relation to the data collected from all sites. Data were subjected to constant comparative analysis[16] which incorporated three iterative steps. First, the analysis team read all transcripts and early impressions were recorded. Second, transcripts were coded by smaller groups; these codes informed the construction of thematic table. Finally, each site's researcher initially coded transcripts using the thematic table and a proportion of its transcripts were cross-coded by another team member. Data analysis was managed using NVivo (version 8); regular analysis clinics generated thematic discussions and considered emergent issues and themes. Overarching themes were noted and reflected on by all.

Table 1. Number and type of interviews by research site.

Site	Prospective interviews			Retrospective interviews		
	Patient only[a]	Carer only	Dyad	Patient only[a]	Carer only	Dyad
S1				3		3
S2	8	10	5	4	8	3
S3	2		6	1		2
S4			1			
Total	8	9	12	5	1	18

[a]People with subjective memory problems, cognitive impairment or early dementia.

Results

A total of 53 participants was interviewed across the four sites (S1–S4) (Table 1): 27 patients (people with memory problems) (13 men and 14 women) and 26 carers (six men and 20 women); 20 were matched pairs. All were white British or European, except for one South Asian matched pair. Half of the carers were spouses. Almost all people with memory problems were retired with only two working part-time; seven carers were employed full-time. Thirty participants were aged 65–79 years; 15 were younger than 65 years and six were older than 80 years. Of the 27 people with memory problems, eight had already received a diagnosis of dementia at the time of first interview (a mixture of diagnoses) and 13 received a diagnosis by the time of the second interview. Those who were thought to have mild cognitive impairment were expecting to be followed up in a year's time.

In terms of communication with professionals, people with memory problems and their carers considered two areas as being of the utmost importance to them during the potential transition to receiving a diagnosis of dementia; being kept informed during the assessment process; and being told the outcomes of the assessment, including the results of tests and the diagnosis, if this could be confirmed.

Being kept informed

There were two aspects to this theme: the need for professionals to ensure understanding and manage expectations during the assessment process; and the need for memory clinic professionals to provide specific information about local services.

Understandably, people with memory problems may not remember what they are told. However, both participants with memory problems and their carers could recall little information about the assessment process in terms of what they were told would happen and how long this would take. There were multiple examples of this lack of clarity. One carer had been told that scan results would be sent to their GP but with no idea of when (S3; C14). There was variation in participants' expectations and understandings of what the assessment and diagnostic process involved; one participant with memory problems expected the whole process to be over in a fortnight:

> '*He (GP) referred me to the memory loss clinic, when they were taking tests and what have you. Then it went on from there and I thought I'd go in and do a couple of weeks and then I'll go, but it wasn't like that. It took a long time'*. (S3; P8)

Few participants with memory problems provided any examples of direct communication between memory services and themselves, or their carers, such as letters that could be easily understood. Overall, the memory services appeared to have few mechanisms to enable patients to remain informed. On occasions families had been informed before the patient of the outcomes of the investigations. The use of medical terminology was particularly disempowering:

> *'You had better see this letter which I don't like at all! That's what I am supposed to be like at the moment, but some of those things are what (daughter) told them and they're not quite accurate . . . I didn't think I was as bad as that . . . Apparently I am half mad, half forgotten myself. I haven't really . . . I do lose my words, but I always have done . . . "Euthymic in mood", I don't know what it means . . . '* (S3; P3)

None of the participants had been told or been given written information about the clinic or service they were attending. While some professionals were attempting to help people with memory problems, for example, asking if a patient would like copies of the clinic letter sent to their GP, this was not always taken on board:

> *'He asked mum would she like anybody else to have a copy of the letter and . . . it was really, did they want me to have a letter and mum couldn't quite grasp that, so he had a try a couple of times . . . but she couldn't quite work it out, what he was trying to say to her, but I mean she did say "yes" in the end . . . we got there eventually'*. (S2; C11)

Being told outcomes of the assessment

It appeared important to patients and carers that they received explanations of both positive results and

Box 1. Knowing what is happening: Disclosing a possible diagnosis.

Receiving a diagnosis; positive experiences

'When he (old age psychiatrist) came the second time, he didn't stay for long, but he did give us a diagnosis, what had happened and what it was and who he was going to get in touch with, and that was all we wanted to know really. He did say that any problems at all . . . get in touch with me. I will, you know (be there) . . . ' (S1; C1).

'He could see on the x-rays that he bought up on the computer. He says, like that bit is the Alzheimer's, because the brain is shrinking . . . ' (S2; C10).

Post-diagnostic follow-up: unmet needs

'Quite disturbed because I can't find anything more about it . . . I said I needed to speak to somebody, can you advise me where to go and she said well you are coming on the 17th, but that was two possibly three weeks ago, so I don't know. I'm probably asking for the moon' (S2; P1).

'It was quite a blow, it was, even though you keep the conversation lighter, there's wheels whizzing at the back of my head, thinking I know what happens with Alzheimer's . . . and you don't know what to ask'. (S2; P1).

Lack of a formal diagnosis: unmet needs

'He (doctor) took me in and said things are pretty stable and we'll send for you in a year. He said it wasn't a worry about Alzheimer's or anything at the moment you know. He wasn't worried about that which obviously I was . . . When he turned round and said everything's OK, that's great, you're over the moon when he said it was OK'. (S1; C4).

'It's just not having a name! I just want a name you know what I mean? I just want to know why these things are happening to him and hopefully it's not anything like Alzheimer's and stuff. I just know, because he's not pretending. I mean he's not that sort, you know'. (S3; C5).

Mild cognitive impairment: unmet needs

'Disappointed because I was expecting like a short term thing, where I'd go in and the doctor sees me and the doctor gives me a remedy . . . . If you can't go any further than this avenue, do we go to the next avenue and how do we correct the symptoms of the memory loss?' (S3; P8).

'Well, just consulted with (the psychiatrist), the wife, discussing memory problems, then he gave me this diagnosis of remembering words . . . apparently their information was very good, which doesn't help me when they say that". (S3; P2).

uncertain or negative findings. The type and range of investigations people experienced, including scans, blood tests and memory tests, formed an important part of the assessment process for people with memory problems. Some participants felt that the results of scans were well explained and appeared to accurately relay this information to the interviewers:

> *'I think the doctor in the hospital shown me the scan, and he said this is interesting. He said the right side of your brain has got a blockage and the blood is not going through. Do you understand that and it's affecting the left side?'* (S1; P4)

Others did not receive test results, waited a long time for them, or had to contact different services to obtain results that appeared lost. In a few cases, communication seemed inconsistent, with the delivery of what were thought to be mixed messages (different things by different people), which, unsurprisingly, caused anger and distress:

> *'We thought we were going to get more information than we did . . . we thought we were going to get information about the scan . . . to know what was going on, but we didn't'.* (S2; C10)
>
> *'When mum had the blood tests I asked the doctor, I said ''what will happen about the tests?'', so she said, ''would you like me to ring you?'' and I said' yes please', and I gave her my number and never got the call. So this was one thing I found very infuriating . . . '* (S2; C11)

In terms of receiving a positive diagnosis of dementia, some patients and carers appreciated honest and clear communication and the opportunity for follow-up discussion; sometimes, however, the amount and timing of follow-up were thought inadequate, leading to distress (see Box 1). Where such opportunities were provided, some participants did not necessarily know what questions to ask, especially immediately after receiving a diagnosis. One patient found it unsettling to be told several possibilities for her problems, namely Alzheimer's disease, brain damage as a result of falls, or '*just wear and tear and getting old*'.

Patients particularly wanted to know what was wrong with them if the tests did not reveal any abnormal findings; notwithstanding a lack of a formal diagnosis was frustrating for some. Some, who were clearly told that they did *not* have Alzheimer's disease, found this reassuring. Some were told that they had mild cognitive impairment. Although seemingly accurate from a professional perspective, on its own, without additional information or practical help, this seemed meaningless and therefore was not considered helpful (Box 1).

Where multidisciplinary teams are involved, communication about the diagnosis was not always coordinated among the team before being relayed to patients and families. The process of indirectly

receiving a diagnosis had been particularly traumatic for one carer, and, to some extent, her husband with memory problems. He had been assessed by a psychologist who had written a summary for the consultant, which included a possible diagnosis of Lewy-Body Dementia. The couple had received a copy of this letter without being told the probable diagnosis. This led to considerable distress.

So, in the light of the above, what sort of information provision would be appreciated by people, especially where there is no definitive diagnosis of dementia?

What do patients and carers find helpful?

People appeared to want individually tailored information in terms of amount, content and variety, and for this to be staggered over time. The environment/context in which information was provided was also important; face-to-face (oral) information, supplemented by written information, was considered useful, as was information provided as part of an early intervention service. Most people wanted more information, stating that 'knowing everything was better than not knowing' and that this helped them to 'plan and be aware of things that may happen' (S1; C6). For a minority, too much written information seemed a problem and a few were happy to receive none.

There was no evidence from any participants of receiving a 'staggered approach' to disclosure and information provision. The exception to this was on receipt of a diagnosis of Alzheimer's disease and offer of 'anti-dementia' medication. This prompted review visits to patients at home from nurses shortly after the diagnosis was received. Though the prime aim of these visits was to monitor medication effects, they afforded opportunities for additional communication, such as providing emotional support or practical advice, as well as discussing the diagnosis:

> *'So I said to the doctor that I really think that J needs to go ahead with the medication . . . and then X (name of nurse) took over and agreed to come and meet us which she did, she came here and she was delightful'.* (S3; C9)
>
> *'The nurses said you need to get your affairs in order . . . so we went to the bank and I explained like my mum's in the early stages of Alzheimer's and they advised me which way to go'.* (S2; C11)

Written information about the different types of dementia, at a variety of levels, would be welcome. Most participants had received no written information about their diagnosis though some had received Alzheimer's Society booklets and were satisfied with these. The majority of examples of people wanting more written information came from the carers of people with less common dementias, such as Lewy-Body dementia.

The main benefit to patients and carers of knowing what was wrong was the opportunity, taken or otherwise, to plan ahead. Practical advice about managing personal finances, often from social workers, was welcomed, as was advice on other aspects of personal affairs. Some participants had been given advice about Lasting Power of Attorney from their doctor or nurse. The timing of advice seemed important, with more practical advice preferred after people had had time to come to terms with the diagnosis:

> *'Perhaps the advice on the practical aspects could come later on when you've had time to calm down and realise that it's not all going to happen overnight. It's bad enough it's going to happen'.* (S2; C1)

Role of memory clinics and voluntary organizations

Memory retraining classes and memory strategy groups run by memory clinics were reported to have positive outcomes for patients and carers. Several participants in one study site had attended such weekly sessions. Information which was integrated into these sessions was considered beneficial. They also facilitated opportunities to meet others 'in the same boat' in addition to providing practical strategies for dealing with memory problems:

> *'The memory clinic (group sessions) was helpful in that I realised so many other people doing just the same, I mean, has the same problem. That's always a help, knowing you are not quite so odd!'* (S3; P3)

Those who attended the sessions were given written handouts from each session which were considered accessible and useful:

> *'Well everything's there (in the file) really. It's quite a good folder that. I found it very good because it's a decent size print . . . I found it very helpful'.* (S1; C6)

The source of the information was important to some. One carer had contacted the national Lewy-Body Society to learn about the disease because they had not received any information and she felt it necessary to seek it herself. Being put in touch with relevant local voluntary sector services, such as Age UK and the Alzheimer's Society, was also valued. Carers in particular reported finding the information resources provided by voluntary organizations helpful, including 'buddying' schemes, carers' leaflets and regular newsletters.

Discussion

Main findings

While some participants spoke positively about their experiences, others identified aspects of communication and information provision which could be improved both by memory clinics and by GPs. In terms of the transition to diagnosis, most patients and their families appreciated clear and honest communication from memory clinic staff, backed up by accessible written information. Opportunities for post-diagnostic discussion appeared welcome, especially by groups afforded a supportive environment. However, some participants, such as those diagnosed with a non-Alzheimer's dementia and those who did not receive a formal diagnosis, appeared to have unmet information needs.

Limitations

Our findings represent patient and carer perspectives on perceived practice. We did not seek the views of professionals in the memory clinics or observe their practice, which would have helped in the triangulation of findings. Further research directly observing practice, and more specifically what information is relayed, would be valuable.[12] In addition, we only explored the information needs of people with dementia at the start of the dementia trajectory. Research exploring carers' views highlights that information needs often change over time.[9] Since some of the participants with memory problems who did not receive a diagnosis of dementia may have subsequently had a diagnosis confirmed, it would be valuable to follow them up to explore their experiences.

Policy implications

Information services can improve people with dementia's quality of life.[6] Those diagnosed are less anxious and upset if they have had prior discussion with health professionals about dementia as a possible diagnosis.[21–23] In England, patients can only access memory clinic services via a GP referral. Our results suggest the need for a more formalized discussion between GPs and their patients with memory problems prior to referral. The provision of an information leaflet which outlines what a patient and their family can expect from their local service would be welcomed. Changes in the commissioning of services in England may enhance GPs' roles in this area[24] and commissioning guidance for diagnostic and early assessment dementia services has already emerged.[25,26] Although national guidance is useful in terms of setting evidence-based standards, local services will need to construct flexible diagnostic disclosure pathways, for example in Lewy-Body dementia, where diagnosis may be more difficult and more protracted.

For both people with memory problems and carers, information needs include: preparation for a possible dementia diagnosis, an understanding of the possible scale of people's emotions during this period, ongoing opportunities for questions at the diagnostic disclosure meeting and afterwards, information about specific types of dementia and the potential of early intervention services to offer further staggered opportunities for communication. This research took place while the National Dementia Strategy was being implemented, with the creation, in some areas, of a new dementia advisor service to facilitate information transfer[5]; though only one of the research sites was involved in such a scheme. Despite the introduction of such initiatives, national voluntary organizations, such as the Alzheimer's Society, remain an essential source of information.

Memory clinics first appeared in the 1970s as specialist centres to facilitate early diagnosis, evaluate therapeutic agents and reassure those who had no significant illness following assessment.[27] Until recently, there was no unified definition of their role or function.[28] The memory services in this study offered different services and professionals. Quality standards for memory services are being devised at both international[29] and national levels.[30] In England, memory clinics can choose to undertake an approved process of accreditation[30] with specific targets such as the provision of information and access to post-diagnostic support; nearly 50 clinics have either already been accredited or are in the process of being assessed and this may lead to improvements.

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