

Primary care led dementia diagnosis services in South Gloucestershire: themes from people and families living with dementia and health care professionals

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Competing interests

TF and RC have received funding from the Alzheimer's Society. ED, SI, LG, RJ, and RG have no conflicts of interest.

Authors' contributions

RG, SC and RC designed and ED managed the project. RG, RC, TF and ED trained and supervised the peer researchers; RJ, and the peer researchers undertook data collection tasks; ED, RC, SI and LG analysed the data. RC wrote the first draft of the paper, ED, RC and RG revised the paper. All authors have commented on drafts of the paper. The project was funded by Bristol Health Partners, who have not been involved in data analysis or interpretation.

Abstract

Background: Primary care led dementia services are an increasingly common form of service delivery, however, little is known about how these services are understood by their main stakeholders: the patients, family members and health care professionals. A primary care led dementia services was piloted in the South Gloucestershire area during 2012, in which GPs led the process of assessment and establishing a diagnosis. Of the 26 surgeries in the area, 11 initially agreed to participate in the pilot, with twelve more joining the project by the end of December 2012.

Aim: The aim of this study was to provide a qualitative analysis of the experiences of health care professionals, patients and their families, of the new process of assessment, diagnosis and treatment of dementia within a primary care service.

Methods: Four patients, three care-givers and eight health care professionals were interviewed by peer researchers – all of whom were current care-givers. Interviews were transcribed and analysed using thematic analysis (TA) following Braun & Clarke's (2006) model. Data was also gathered about the number of referrals and what happened to these referrals.

Results: Themes gathered into four main areas: *'the journey'*, *'what next?'*, *'the benefits and limits of primary care'* and *'are GPs getting it right?'*

Conclusions: the analysis provided a perspective on the experiences of patients, family members and health care professionals involved in the relocation of part of the memory service, from secondary care (memory clinics) to primary care, being piloted in South Gloucestershire. This identified both practical issues to be improved upon as well as possible barriers.

Keywords

Dementia, Alzheimer's disease, memory clinics, primary care, diagnosis

Introduction

Background

In the UK recent estimates suggest that roughly 670,000 people have dementia – a figure that is expected to double over the next 30 years (Matthews et al 2013). Yet epidemiological studies show that as many as 50 percent of people with dementia might be unrecognised (Connolly Gaehl, Martin, Morris & Purandare 2011). Thus in the UK, as elsewhere in Europe, there has been consistent pressure within NHS Services towards making the diagnosis of dementia at an earlier stage, and for more people. This has been driven at least in part by an awareness that an early diagnosis both maximises the opportunity for treatment through cholinesterase inhibitor such as donepezil, and also provides the opportunity for people to adjust to the illness. However, the increased demand for early diagnosis places pressure on secondary services, including memory clinics, at a time when health services finances are already stressed. Consequently, increased attention is being paid to the possibility of enhancing the role of primary care teams in the assessment, diagnosis and treatment of people affected by dementia not just in the UK, but also in Canada (Lee et al 2010), USA (Boustani et al 2005), Norway (Engedal, Gausdal, GjØra & Haugen 2013), Ireland (Cahill, Clark & O'Connell 2008) and Crete (Lionis et al 2001).

Primary care and dementia

In the UK, national guidance stipulates that treatment of mild to moderate levels of cognitive impairment due to Alzheimer's disease with cholinesterase inhibitors should be initiated following a specialist assessment (Lindesay, Marudkar, van Diepen & Wilcock 2002). Consequently, the majority of assessments for dementia have been initiated in secondary rather than primary care, and the role of GPs with people affected by dementia tends to be comparatively limited. However, if GPs were to be more involved in the process of assessment, diagnosis and treatment of dementia, then this would have a number of potential advantages. Primary care is ideally placed to recognise and manage dementia as the first point of call and the gateway to other health and social support

services. Moreover, because of their often close and well-established relationship with patients, GPs may be in the ideal position to recognise the initial signs of a possible dementia, and to initiate appropriate assessment and treatment plans.

At the same time, the barriers to effective service provision for people with dementia in primary care have been well documented (Koch & Iliffe, 2010). In addition to patient and community barriers that restrict the initial identification of problems by the medical system, there are also other barriers to effective diagnosis. Thus most GPs tend to have relatively little experience of working with people with dementia. For instance in the UK, a typical GP might expect to have only one or two patients every year diagnosed as having dementia, and have between twelve and fifteen patients at any one time with this condition (Iliffe et al 2009). Similarly, primary care physicians often cite the absence of ring-fenced time as a major factor leading to their inability to provide a specific dementia service (Olafsdottir, Foldevi & Marcusson, 2001; Turner et al 2004). Lack of knowledge amongst GPs about dementia, and a reluctance to make a diagnosis can be particularly problematic for people from specific groups, such as people with learning disabilities or younger people with dementia (Iliffe, Wilcock & Haworth, 2006).

Primary care led dementia services

Although at least two other service frameworks have been described in which assessment takes place in primary care, in both instances this has been due to specialist staff coming into primary care, rather than primary care health team themselves developing new skills. Thus the model adopted in Gnosall, Staffordshire, involved integration of a monthly memory clinic within every GP practice (Greening, Greaves, Greaves & Jolley 2009). A consultant psychiatrist was available for contact at all times and main coordinator of care was appointed, labelled as the 'eldercare facilitator' (Greaves et al 2013). The Croydon Memory service (Banerjee et al 2007) is a complementary service involving professionals from health, social and voluntary services within the

area to provide individually-tailored approach of assessing and managing people with dementia. All professionals within the services receive the same training about dementia and its management, and their role is to assist early recognition and assessment of people with suspected dementia.

Evaluations of these models suggest that early diagnosis of dementia within primary care offers improvements in quality of life (Bannerjee et al 2007) and is an acceptable and effective service (Greening et al 2009).

South Gloucestershire Model of primary care led dementia diagnosis

A primary care led dementia service was piloted in the South Gloucestershire area during 2012.

Unlike the models in Croydon and Gnosall, in South Gloucestershire GPs were expected to take the lead in assessing, making a diagnosis and providing treatment for patients suspected of having a dementia. This involved GPs assessing patients aged over 75 using the Mini-Cog, which is a brief screening tool (Borson , Scanlan, Brush, Vitaliano & Dokmak 2000), blood tests and (where necessary) a CT head scan to exclude other possible causes of memory impairment. Those people who were aged 75 or under or who presented with atypical symptoms or “*red flag*” symptoms such as behavioural changes and expressive language problems would continue to be referred into the secondary care memory service for a specialist assessment.

Of the twenty-three GP surgeries in the area, eleven initially agreed to participate in the pilot, with twelve more joining the project by the end of December 2012. At the outset of the pilot service, it had been intended that memory nurses would be attached directly to participating surgeries, but as more surgeries joined the project, so this became unfeasible. Instead, the memory nurses were located centrally, so that if a GP at a participating practice wanted further clarification before diagnosing and offering a cholinesterase trial, they had the option of contacting the primary care memory service for advice and support. Service users from participating practices who were on the memory service review caseload were discharged back to their GP for annual review (see Figure 1).

Aim

The aim of this paper was to investigate how the South Gloucestershire primary care memory service was experienced and understood by all those involved in the dementia diagnosis process. We sought to incorporate each participant's experience and the meaning they attached to these and to establish themes from each of the three main stakeholders (people affected by dementia, carers and health professionals).

Study design

Theoretical framework

We sought to collaborate with people with dementia, their family and friends and those working in health and social care services to enable an in-depth understanding of primary care based dementia assessment from a range of different perspectives. The study therefore employed peer interviewers in the belief that this would confer a number of advantages over professional researchers – not only do peer interviewers have a unique perspective on caring for someone with dementia, but their caring experience might enable them both to be more empathic when conducting interviews and to be positioned as colleagues, rather than interrogators. It was felt that peer researchers may enhance the authenticity of participant responses because they share a greater sense of trust and empathy with the patients and carers.

Participant selection

Two GPs were able to identify potential patient participants, yielding one service user and one carer. The remaining service user and carer participants were identified through the Primary Care Liaison Service. This service operates alongside GPs to assess patients thought to have mental health concerns - and then either liaises with GPs to plan treatment and care or makes a referral to secondary care mental health services including the memory service. All the service users who were interviewed in this study had only been seen by their GP and not by memory nurses working in either primary or secondary care memory service. Recruitment of GPs was via email invitation to GPs direct or via telephone conversation with practice managers.

In total thirteen people affected by dementia and their carers were approached to take part in the study, of whom four people affected by dementia (two male and two female), and three carers agreed. Six declined to take part. All eight health care professionals who were approached agreed. All interviewees across all three groups defined themselves as being of white European.

Setting

All interviews were conducted in a location chosen by the participant. Generally, for patients and their relatives, this was their own home while for professionals it was their place of work (e.g. GP practice, memory clinic). On three occasions, patients and their relatives were interviewed together, but all other interviews were conducted on a one-to-one basis.

Data collection

Seven interviewers were recruited to carry out the interviews. These “peer” interviewers had personal experience of caring for a family member with dementia and were either current or former care-givers. All of the peer researchers were female and they had an average age of 62 years. (age range 50-77 years) They were all well educated; a couple had been involved in other Patient Public

Involvement (PPI) activities within the university and others had previously worked in educational institutions at various levels. A one-day training programme was provided to ensure that peer researchers were confident and competent in conducting interviews with people with dementia, family members and health professionals. RG, RC and ED facilitated the training day which consisted of an overview of dementia, the role of the interviewer, interview skills and techniques, familiarisation of the interview schedule, recording equipment and procedures, including consent. Different training methods were used, including role plays. Support and supervision arrangements during the project were addressed; group and individual supervision via the telephone was provided. Following Involve Guidance, all interviewers were paid for the hours they worked and were reimbursed travel expenses.

The semi-structured interview schedule used in this study replicated that used in previous work (Dodd et al, 2014). This was developed from feedback from a panel of memory clinic and other experienced health care workers. This initial draft was reviewed and extensively modified during further focus group meetings made up of professionals and a separate focus group made up of carers and families affected by dementia. Questions for patient and carer participants centred on events leading up to diagnosis, the time whilst getting a diagnosis and post diagnosis including treatment, support and advice. Questions for Health care Professionals focused on screening and diagnosis, medication, training and opinions on service design.

Interviews were audio-recorded using digital recorders with recordings being stored on a secure, encrypted SharePoint site, password protected and accessed by the transcribers and evaluation team only. All identifiers were removed from the transcripts to maintain anonymity and confidentiality. Due to time constraints, transcripts were not sent to participants for checking.

Research team and reflexivity

The research team were a mixture of males and females, of a range of ages and were educated to at least degree level or above. Most had recent secondary care clinical experience of working with people with dementia. The research team included psychiatric nurses (RJ, RG), a primary care nurse (TF), a psychologist (RC), a project manager (ED), an old age psychiatrist (SC) and research assistants (SI, LG).

Data analysis

Interviews with the patients or family members and the interviews with the health care professionals were transcribed and analysed using Thematic Analysis. Braun and Clarke's (2006) six-phase guide was strictly followed when carrying out the thematic analysis to maintain rigour in the analysis process. The analysis was carried out by four members of the research team (RC, ED, LG and SI). Initially, each researcher familiarised themselves with seven of the interviews and generated their initial codes separately. Each transcript was analysed by at least two researchers, with the transcripts allocated so that each rater read an even mixture of transcripts from the three different groups. RC and ED coded by hand while LG and SI used the qualitative research tool NVivo 10.

The initial codes were then brought together to ensure similar ideas were being similarly coded and a rough thematic map was drawn up so that emerging themes could be identified. Following this discussion, each researcher was allocated a separate theme and went back to the data to group together relevant codes in order to substantiate the initial themes and sub-themes. The researchers came together once more to review the themes and sub-themes which emerged and to identify possible overlaps and repetition. During this review the thematic map was revised (Figure 2) and from this the analysis was developed.

Analysis and findings

Consolidated Criteria for Reporting Qualitative research (COREQ) standards have been adhered to throughout the report (Tong, 2007)¹.

Referrals to memory services

Over the six month period between June and December 2012, a total of 139 patients were assessed in primary care, with 141 referrals being made to the secondary care memory service. Of the 139 people who were seen in the primary care memory service, thirteen (9.4%) were referred onto other services (including secondary care memory services) and eleven (7.9%) declined the offer of an assessment. This is similar to the numbers of people seen in secondary care who were referred on (sixteen or 11.4%) or who declined the offer of assessment (eleven or 7.8%). Thus roughly half of all the patients in South Gloucestershire who were assessed for dementia during this period, were seen solely within primary care.

Qualitative findings

Four themes were identified during the analysis: the journey; what next? the benefits and limits of primary care; and are GPs getting it right?

Theme 1: The Journey

When talking about the diagnosis process, participants repeatedly spoke as if they were describing a journey, focusing on the sub-themes of *time*, *transformation* and *adjustment*. These three characteristics, which occurred repeatedly within the data, are key concepts that help to describe the overarching theme of 'the journey'.

¹ Ethical approval was obtained from the ethics committee of the University of the West England (Reference number: HLS/12/10/114). The research and development departments at Avon and Wiltshire Partnership NHS Trust and the Avon Primary Care Research Collaborative also approved the study as a service evaluation.

Time

One of the main arguments used within the move towards a primary care led service was the hope that it would enable a diagnosis to be reached more quickly. It is therefore not a surprise to find professionals advocate this aspect of the new service:

So in primary care that process is much quicker, so you can see your GP, you can ... you know ... you can have a diagnosis almost immediately if the GP is confident enough to make it but even if the GP wanted our support and help you know within four weeks we can have assessed

[female HCP]

Participants typically described the process through which a diagnosis was achieved as something that both needed, and took, time to obtain. The assessment also needed to be timely, and to occur at the right point for patients and their families. Participants expressed concerns that the diagnosis might happen too fast for the patients to come to terms with it appropriately. So, within this frame, a timely diagnosis should not happen at too fast a pace:

That [assessment] can take a few weeks which is actually quite useful because it gives the family time to start actually documenting what is going wrong and it gives the patient time ... I always call it memory problems rather than dementia, so it gives them time to think about it

[female HCP]

... Actually sometimes [within primary care led services] it happens too quickly and people need time and a process to follow to help them to adjust to the idea that they've got a memory problem and it's kind of ... a bit more of a journey for them whereas you know that can just be a bit of a shock really when it happens so quickly.

[female HCP]

Transformation

Another aspect of the journey was its transformative power – that during the journey the individual moved from a non-stigmatised position of being a person to one in which they were identified as having dementia and at risk of the stigma that is associated with this.

Interviewer: *So this idea about memory problems came out of the blue then?*

Respondent: *Oh absolutely and if she (the GP) had never gave me that test I don't suppose it would have arisen at all ... I wouldn't have been seeking advice myself because it's an admission of failure if you like.*

[, male with dementia]

Similarly, relatives spoke of the emotional cost of the changing role of becoming a carer to their relative who had been given a diagnosis of dementia:

"Yes I was sad because this is my mum who has always done for me and even when she lost her eyesight there were still things she would be able to do and now she's not able to do any of those things...I realise I have to harden up for her good really"

[female relative]

"...when he gave us the diagnosis and he said "of course you will be his carer" and I went "oh", you know, what is ahead of me"

[female relative]

One GP was also concerned about what he described as the "major ramifications" involved in giving someone a diagnosis of dementia:

I think personally as GPs and as health professionals we need to be very careful that we don't screen and give people these labels because these labels carry massive weights around people you kind of on reflection its probably been there for 10 years ... and you might make the diagnosis and is that a bad thing that they have not lived with that stigma of that diagnosis? Because there is a stigma associated with it if they functioned OK and it's difficult to know if that's a bad thing or a good thing

[male HCP]

But, at the same time transformation can also be positive - for example, it can allow people to gain access to treatment and support that they can benefit from:

Dementia. It's opening doors to people rather than closing doors. It should be sort of to services ... accessing services such as ... you know ... exemption of Council Tax and all those sort of things and kind of making sure ... the carer or you know the spouse has got information on benefits and that, sort of knowing where they can get support. ... because the diagnosis doesn't actually help the ... well it may help the ... you know people around them to manage and sort of understand what they're doing and the teaching and training but it certainly doesn't necessarily change anything at home. It's more about what they can access.

[female HCP]

Adjustment

The transformation inherent in the journey requires people to make an adjustment. Thus after being given a diagnosis, relatives in particular spoke of attempting to adjust to the news; dealing with the unknowns of how the diagnosis would impact on day to day life:

“It’s going to be very difficult because I didn’t know what was coming ... I have to be a bit of a detective, if I haven’t heard him doing something I’ll say have you done so and so?”

[female relative]

And reflecting on how it impacts on the person with dementia themselves

“...when you find other things to do like to replace that, she seems to have lost interest in it and she would be quite happy to sit in that chair all day”

[female relative]

Finally, for people affected by dementia, the problematic aspects of dementia will vary – for some this may be represented in having to give up driving, while for others the realisation of change came in different ways:

“The doc recommended I gave up driving and to me that was like a smash in the face”

[male with dementia]

“I think um I wouldn’t think I was sort of inadequate suddenly it was a reminder that I am getting older now somehow ...I haven’t taken the seriousness of how old I am you know I still think younger if you like whereas I know some people who are of a similar age to me and they think as an old man I am not thinking like that”.

[male with dementia]

The transformation inherent in the journey can be isolating for both the person affected by dementia, and also their families

there’s a lot of people out there that are lonely and isolated that go sort of unnoticed really and so I think if maybe ... there was somebody ... a named person ...a specialised Dementia

face and name that they could ... you know that families could ... you know so publicise that this is where you can get the help

[female HCP]

Theme 2: What next, what happens after the diagnosis?

The way in which service users and relatives cope and are subsequently supported after receiving a dementia diagnosis were concerns raised across the interviews. There was a sense that the patients' journeys had just begun but then no one was really sure what they should do next. The largest pattern within this theme was a concern about a lack of coordinated support post diagnosis.

Care coordination gap

There was a consistent feeling that follow-up and support post-diagnosis is sometimes lacking. In particular a number of interviewees described a system in which people affected by dementia were signposted to services but there was no one agency that was responsible for coordinating and following up people to ensure that needs were being adequately met. This included carers:

"Sometimes they [the surgery] don't chase up though"

[female relative]

And also health care professionals including nurses and GPs:

"...there appears to be very little provision of consistent services that people appear to find most helpful (care coordinating and providing on-going support to patients and families) ... everyone signposts to everyone else but no one takes overall responsibility for care coordination"

[female HCP]

"We're not care co-ordinators ... we don't get involved in the co-ordination because the peoples' involvement with our service is too short term. What we do have a responsibility for is signposting people and making sure that they can access and know about and understand the support that is available for them

[female HCP]

I am happy to be the doctor coordinating the kind of medical bits of checking they haven't got any physical reasons and treating the medication and checking the medication is fine,

but the kind of psycho social support of families and with that it would be nicer to have somebody else

[male HCP]

Families and care

Concerns around the co-ordination and effectiveness of support related not just to statutory services, but also to the support that families themselves offered. For some families, the care was effective:

“Four of them, two sons and their wives and they all mucked in...it was very good ... “well there again, we told my daughter in law and she was full of information. So she was very, very good””

[female HCP]

For other families there was a sense of feeling let down by other family members who were represented as not pulling their weight to help and support, leading to a greater reliance on the state:

“Why should I be sending off for all these things when I’ve got two brothers and a sister, why can’t they be having her one day a week? Or a weekend or doing something different with her, take her out for a day? ... I’m going to have to say I need somebody because I can no longer bath mum. ...you ask them [family member] to come and oh, oh I forgot that bath; it’s no good mum’s got to have a bath”

[female relative]

Medication

One of the strongest arguments to support the introduction of a primary care led dementia service is that an early and timely diagnosis facilitates access to medications, including acetylcholinesterase inhibitors. However, health care professionals differed in the value that they placed on prescribing medication. One health care professional highlighted what they believed to be the positive benefits to prescribing medication:

“...when something like donepezil is so well tolerated by so many people it’s no biggy to give him a try it and see if it suits them and if it doesn’t and whether its Alzheimer’s or vascular dementia a lot of them have a bit of each and if it helps them who cares a stuff which one it was”

[female HCP]

Others within the health service were more sceptical, wondering if the medication takes away the focus on the real support needs of the service user and family:

“I think there is far too much emphasis on diagnosis and handing out tablets that give false hope to patients and carers”

[female HCP]

Similarly, people affected by dementia and their families had mixed views – with some noting that the medication had needed to be adjusted:

“He has some tablets before which made him violently sick he had two goes at them but couldn’t handle them and so he went back to the doctor and he said we’ll try these [patches]”

[female relative]

Theme 3: Benefits and limits of primary care

The extent to which memory services could be effectively assimilated into primary care was a major theme running throughout the interviews with all three groups of participants. Two sub-themes were identified relating to reactions to the new service and the continued relevance of secondary care.

Reaction to the new service

Participants described a mixture of reactions towards primary care led memory services. Much of the positive reactions seemed to come from patients and carers, while the majority, but by no

means all, of the scepticism came from health care professionals. One concern for GPs was that a 10 minute appointment will not be long enough.

Because you can't say oh I think you have got dementia, right, diagnosis, outside, 10 minutes all done

[female HCP]

I think we would love that to happen, but the agenda from the Government at the moment is that everyone should be able to see their doctor instantly ... the more and more instant accessibility we have to have the less and less routine appointments ... in 10 minute slots where it's probably not a sufficient time to do that review justice.

[male HCP]

For patients and carers, however, many participants felt they were taken seriously and that they were listened to. One person affected by dementia reported:

Yes always listened to ... everyone seemed sincere enough ... I can never remember being next, next, come on, next patient please. Looking at the watch all the time you know

[male with dementia]

However, when they were asked if they were happy with the amount of information they had been given, participants gave mixed messages. Some felt they were given too much information and that they were overwhelmed and others felt they were given little to none – for instance one participant felt she had to rely on their daughter for all the information they wanted, while another felt she had to do her own reading around the diagnosis.

Another concern that was raised by some health service staff was that GPs might be reluctant to use the term “dementia” and instead use euphemisms such as the term 'memory problem'.

Interestingly, it was the memory nurses who seem most aware of a need for clarity amongst GPs.

Probably the biggest difficulty that I've observed this far, is that a number of people are not receiving accurate diagnosis and we can only surmise as to why this is but GPs are not using the word Dementia when they diagnosis (sic),

[female HCP]

Finally, concerns were expressed by health professionals that the prime motivation in establishing a primary care led dementia service was not to improve the quality of care but to make financial savings:

There are some sort of sceptical views as to why it's ... originated to and you know there is a sense as well that you know it's no coincidence that the primary service evolves at the same time as the drugs are taken off licence as well. So the NICE guidelines have changed at the same time as our primary service was introduced.

[female HCP]

Secondary care is still needed

Regardless of the merits of a primary care led service, a number of participants emphasised that the expertise and support from secondary care was still sought after and welcomed by primary care staff. The distinction was made between complex cases (involve co-morbidity, accompanying psychosis or unusually young diagnosis) and straightforward cases (cases GPs are used to and are comfortable with diagnosing for themselves):

I mean the reason I say that there are some aspects that I'm not confident about is because ... there are very many different kinds of Dementia now and some of the more complex Dementias ... those are areas that fall within the expertise of our clinical psychologist and our lead doctor as well.

[female HCP]

I think if I had someone who was in their 50's or in their 60's early 60's and still kind of working and you know I think it's much... I wouldn't feel comfortable in being the sole person managing that person because I think they require much more formal testing and you know formal support ... I would rather look after patients with a management plan from secondary care with the knowledge that I can refer back into secondary care if I get into problems

[male HCP]

In addition to their specialised assessment function, secondary care memory services also provided support which some people who had been diagnosed in primary care were also able to access provided that a specific referral for this was made:

"...the memory nurse has been and we went on a course for six weeks"

[female relative]

“she [memory nurse] always said if there’s any problem or anything you want to ask you’ve got the telephone number just come back to us anytime you want to... she [memory nurse] was also taking on board my role as well”

[female relative]

Theme 4: Are GPs getting it right?

This broad theme focused on whether a primary care led dementia service (and in particular GPs) had the necessary skills and experience.

Training

Although most of the health care professionals who were interviewed described having some training in dementia as part of their professional qualification, most were ambivalent about its value. Rather than training being identified as enhancing their competence, health care staff consistently maintained that it was best to learn from experience and from their colleagues:

Yes, I mean I’ve been nursing now for 29 years and I’ve always worked with Dementia so it’s kind of like my passion really to you know ... so as nursing a lot of it is you learn on the job, you see other people doing it.

[female HCP]

Very little [training], post registration. I have attended various short courses in subjects such as dementia care mapping, person centred care and end of life care. I have learned the processes of being a memory nurse by, initially shadowing another memory nurse, then by being surrounded by other team members ... The most helpful has been learning from colleagues and the sense of serving an apprenticeship.

[female HCP]

This was the case for Doctors as well as for the nurses:

I: ... would you like more say more training do you think you could do with some more?

R: No because they gave us a lot of advice they gave us a lot and we can access it, it’s just having the memory nurse to fall back on really.

[female HCP]

...you know when I joined this Trust and they talk about Alzheimer's and you know sort of Dementia. I did a few day course ... I can't remember ... I think it was a three day course on specifically Alzheimer's which was run by ... the Alzheimer's Society.

[female HCP]

Evolving the diagnosis: multi-disciplinary consultation?

Supporting this account of the importance of colleagues, participants often described the process of assessment and diagnosis as a collaborative or multidisciplinary exercise, albeit one in which there are clear boundaries between roles, with the nurse carrying out the assessment and the Doctor making the final diagnosis:

...Well I wouldn't make a diagnosis of Dementia; I would make an assessment of the mental health. The emphasis is very much on getting GPs to make the diagnosis so very often I would be compiling my assessment; using some testing to compile evidence and then take a history and all the rest of it. Rule out other mental health problems and then if it appeared to be consistent with Dementia, advise the GP and the GP would make the diagnosis.

[male HCP]

These clear boundaries are evident from the relative's perspective as well:

When she came she [the nurse] said she would send a report back to the doctor with what she felt was going on and would I make an appointment in about a fortnight's time to discuss it with Dr. [name] and I did, I did that and that's when mum started to have the patches. [okay]. Yes from that time so it was on her recommendation.

[female relative]

Even though GPs had the responsibility to prescribe medication, they made some of those decisions in consultations with other professionals. Also, the inputs by these other professionals were considered invaluable.

After initiating [medication] I would review it four to six weeks later although the memory nurse said I can do it eight weeks later and then I would have a discussion with the memory nurse, I normally keep a list of all the patients that are started I talk to her about it and she would sort of give me advice and one of those patients she has actually asked me to stop

medication and they are the ones that are being referred to the memory clinic for second opinion I have found that invaluable I don't think I would be happy to do it without the back up of a memory nurse

[female HCP]

However, in other instances, the opinions or recommendations of the other professionals could be over-looked or rejected:

Well I'm not a doctor so I can't diagnose, no, but I can contribute to the gathering of history and advise the GP. What I generally say is words something like you know, 'the evidence of assessment' and 'the history is consistent with a diagnosis of Dementia which may be of the vascular type if you choose to make that diagnosis'. Sometimes they do, sometimes they don't.

[male HCP]

Discussion

This paper presents a thematic analysis of the experiences of people affected by dementia, their families and health care professionals of a newly developed, primary care led dementia diagnosis service. Although the numbers of people who were interviewed are relatively small this study has attempted to identify the experiences of all those people involved in the process, both health care professionals, as well as people affected by dementia and their families. This is a small scale qualitative study; it's aim is not to produce a generalisable piece of work but rather to gain a better understanding of the participants' experience and generate ideas that further research can properly test. The analysis suggests that in many cases broadly similar concerns were held by many of the participants, regardless of how they had encountered the memory service. The identification of themes underlying the experiences of interviewees is of interest in its own right, but also as a means of generating areas for future research.

A central methodological issue concerned the use of peer interviewers. Although the way in which peer interviewers could be positioned in a different way from academic or clinical researchers,

brought a number of methodological benefits, this approach could also bring conceptual risks. In particular as naive interviewers they might frame the interview in a way that reflected their own biases. Thus it may be that in their encounters with people affected by dementia and their families, the peer researchers may have engaged more readily with the carers' perspective, than with the person affected by dementia. The strength to this approach is that it is likely that peer researchers may have elicited material that may have not been so easily accessible from conventional methods. The use of peer researchers has been used in other areas of mental health research (Rose, Leese, Oliver et al 2011) and in studies with care home residents (Goodman, Mathie, Cowe et al 2011) suggesting that it does have a role to play in dementia research as well.

Although each of the three groups of participants might be thought to approach this area from a particular stand point, it was possible to identify a number of consistently expressed concerns.

Lack of post-diagnostic co-ordination

A number of participants expressed concerns that not only was not enough support available for families, but that the lack of a co-ordinated approach meant that some families might not be able to draw on the support that was available. Thus some families described not receiving enough information (perhaps because the GPs in this Pilot study didn't yet know enough about dementia or know where to find information about it), whilst others felt that the care that had been promised or indicated was not forthcoming. These concerns about a post-diagnostic support gap echoes fears expressed nationally (e.g. Watts, Cheston & Moniz-Cook 2013) that the concern of policy makers to increase the number of diagnoses that are made in the UK has not been matched by a concern to make resources available to support people who have received a diagnosis. Placed within this context, the site where the diagnosis is made and communicated, is of less importance than whether people affected by dementia then receive adequate and appropriate levels of support. At the same

time, a number of participants in the study expressed frustration not just with the statutory services and the third sector, but also within their own families that others, who they felt should also have taken more responsibility had not come forward.

GP led or multi-disciplinary assessment?

Although the South Gloucestershire model is primary care led, this does not mean that secondary care services were not involved. Rather it involved a stepped approach to making a dementia diagnosis so that where a diagnosis was complex or uncertain, patients could still be referred to the memory service for a comprehensive diagnostic assessment. Moreover, support from secondary care services was also available for GPs, for instance through memory clinic and primary care Liaison nurses. This is consistent with an evaluation of a similar primary care led dementia service in Bristol suggested that GPs rarely make independent dementia diagnosis and that instead GPs and memory nurses worked closely together (Dodd et al 2014).

Many interviewees echoed the need for support from specialist services by describing concerns that have been expressed elsewhere in the literature, for instance that GPs can find it difficult to disclose the diagnosis to patients or family appropriately (Koch & Iliffe 2010) or that they may use euphemisms for dementia (Iliffe, Wilcock & Haworth 2006). Arguably the most critical barrier preventing effective primary care services from working with people with dementia is the feeling of a lack of support from and communication with secondary care (Koch & Iliffe 2010). This includes a lack of knowledge about and access to other forms of community support such as from the third sector. Although GPs and specialist health care professionals in this research emphasised the importance of experience over training, it is unclear whether GPs see enough people affected by dementia to confidently and competently diagnose dementia and to rule out other diagnoses.

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Figure 1: Pathway of Diagnosing Dementia in Primary Care in South Gloucestershire

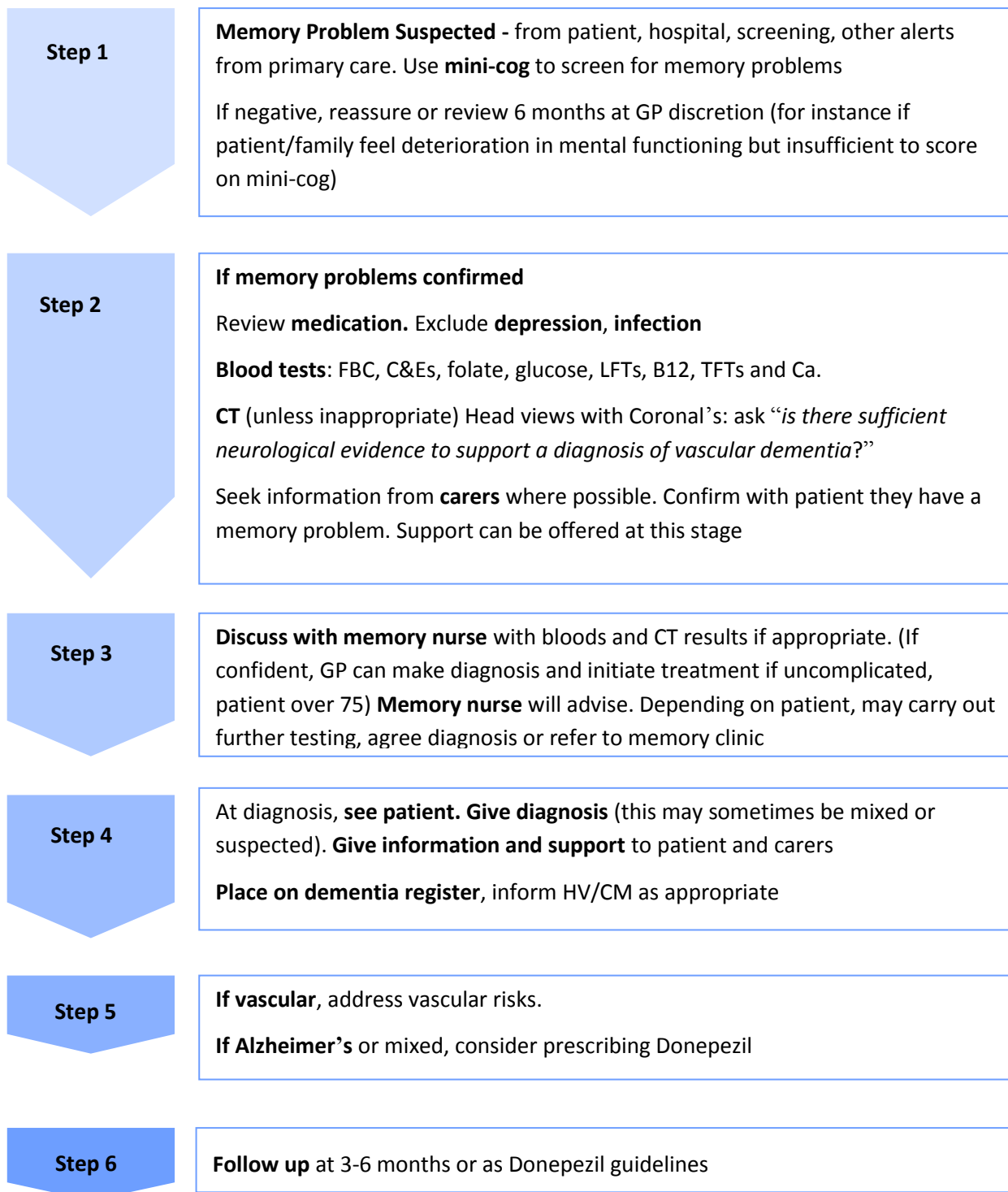


Figure 2: Thematic map

