'Timely' Diagnosis of Dementia: What does it mean? A narrative analysis of GPs' accounts

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Complete List of Authors:	Dhedhi, Saadia; Barts and The London School of Medicine and Dentistry, Queen Mary, University of London, Centre for Primary Care and Public Health Swinglehurst, Deborah; Barts and The London School of Medicine and Dentistry, Queen Mary, University of London, Centre for Primary Care and Public Health Russell, Jill; Barts and The London School of Medicine and Dentistry, Queen Mary, University of London, Centre for Primary Care and Public Health
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'TIMELY' DIAGNOSIS OF DEMENTIA: WHAT DOES IT MEAN? A NARRATIVE ANALYSIS OF GPs' ACCOUNTS

Saadia Aziz Dhedhi* (corresponding author)
Medical Student

Deborah Swinglehurst* (guarantor)
NIHR Senior Clinical Lecturer

Jill Russell*
Senior Lecturer in Health Policy and Evaluation

* Centre for Primary Care and Public Health, Barts and The London School of Medicine and Dentistry, Queen Mary, University of London, 58 Turner Street, London E1 2AB

Correspondence to:
T: +44 7958 508 293
E: ha09131@qmul.ac.uk

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ABSTRACT

Objective To explore general practitioners' perspectives on the meaning of 'timeliness' in dementia diagnosis.

Design Narrative interview study.

Setting UK academic department of primary care.

Participants Seven practicing GPs with experience of conveying a diagnosis of dementia.

Methods GPs' narrative commentaries of encounters with patients with suspected dementia were audio-recorded and transcribed resulting in 51 pages of text (26,757 words). Detailed narrative analysis of doctors' accounts was conducted.

Results Diagnosis of dementia is a complex medical and social practice. Clinicians attend to multiple competing priorities whilst providing individually tailored patient care, against a background of shifting political and institutional concerns. Interviewees drew on a range of explanations about the nature of generalism to legitimise their claims about whether and how they made a diagnosis, constructing their accounts of what constituted 'timeliness'. Three interlinked analytic themes were identified: 1) Diagnosis as a collective, cumulative, contingent process 2) Taking care to ensure that diagnosis - if reached at all - is *opportune* 3) Diagnosis of dementia as constitutive or consequential, but also a diagnosis whose consequences are unpredictable.

Conclusions Timeliness in the diagnosis of dementia involves balancing a range of judgements and is not experienced in terms of simple chronological notions of time. Reluctance or failure to make a diagnosis on a particular occasion does not necessarily point to GPs' lack of awareness of current

policies, nor to a set of training needs, but commonly reflects this range of nuanced balancing judgements, often negotiated with patients and their families with detailed attention to a particular context. In the case of dementia, the taken-for-granted benefits of early diagnosis cannot be assumed, but need to be ‘worked through’ on an individual case-by-case basis. GPs tend to value ‘rightness’ of time over concerns about ‘early’ diagnosis.

Article Summary

Strengths and limitations of this study

- Adopts a novel methodological approach, based on narrative analysis, to explore the meaning of ‘timely’ diagnosis of dementia in general practice, addressing an important gap in the research literature.
- The methodological approach adopted generates insights that cannot be gained from more conventional approaches to interviews and analysis.
- The study findings have important implications for practice and policy, suggesting that current policy efforts to increase rates of ‘timely’ diagnosis runs the risk of increased rates of ‘untimely’ diagnosis
- Prioritises depth of analysis over breadth, each interview generating a large amount of data for analysis.
- The interview participants may not be typical of all GPs in how they approach the diagnosis of dementia

INTRODUCTION

The diagnosis of dementia is high on the health policy agenda. The last few years have seen a proliferation of reports and calls for action for the early diagnosis of dementia, nationally and internationally (1-4). In March 2012 David Cameron, launched the 'Prime Minister's Challenge on Dementia' (5), announcing a commitment to address the 'shockingly low' diagnosis rates for dementia in England (6) (only 42% of people with dementia have a formal diagnosis, according to the Department of Health (5)). In 2013 the NHS Commissioning Board published plans for a new enhanced service "for take up by GPs as part of the GP contract for 2013/14 to reward practices for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia" (7).

An increasingly widespread view is that 'timely diagnosis' is a more appropriate concept than 'early diagnosis'. 'Timely' implies a more person-centred approach and benefit to the patient, and does not tie the diagnosis to any particular disease stage (8). Some commentators distinguish between 'timely', meaning at the right time for the particular patient in the specific circumstances, and 'early' diagnosis in the chronological sense (9; 10). More often the two terms are used interchangeably, disregarding their different meanings, and with the emphasis firmly on *early* diagnosis. Policy documents invariably present the benefits of early diagnosis as axiomatic, although in the medical press and research papers the possible harm of 'premature diagnosis' is widely voiced (8; 9; 11). Table 1 identifies the common arguments for and against the early diagnosis of dementia.

<INSERT TABLE 1 ABOUT HERE>

Largely missing from the policy debate is empirical evidence of how doctors in the front line of diagnosis, typically GPs, construct, interpret and manage the concept of timeliness. In media reports GPs are invariably portrayed as barriers to diagnosis, and accused of “grim fatalism” (6). Implicit in much research on this topic is a ‘deficit model’ of GP behaviour and attitudes; a common assumption is that GPs are not necessarily acting in the best interests of their patients in how they approach diagnosis. The research focus then turns to uncovering the ‘constraints’ and ‘barriers’ to earlier diagnosis (12-15), often resulting in proposals for educational interventions to improve GPs’ rates of diagnosis.

A growing body of research is emerging which highlights that GPs, far from acting out of ignorance, consider the diagnostic process as a nuanced weighing up of many different factors, varying between patients depending on the specifics of each case (16-20). Furthermore, these studies highlight that diagnosis is not a single event, but an evolving process. Whilst such studies have contributed significantly to our understanding of GPs’ experiences of diagnosing dementia and factors impacting on early diagnosis, none has considered specifically the much used but poorly understood concept of timeliness.

Existing research suggests it is time to study GP practice in relation to diagnosing dementia from a fresh perspective, one that does not take a deficit model as its starting point, and critically, one that captures its contextual and evolving nature. This paper presents findings of an in-depth study of UK GPs which aimed to explore, from a narrative perspective, how the notion of 'timeliness' is constructed in practice, and how GPs account for the decisions they make about the diagnosis of dementia.

METHODS

This study was undertaken as part of an intercalated BSc Global Health dissertation between November 2012 and May 2013. It received ethical approval from the Queen Mary University of London Research Ethics Committee (reference 1071). We were interested in finding out what a 'timely' diagnosis means to GPs and how GPs represent themselves as "agents acting in life worlds of moral complexity" (21). We chose a narrative methodology because of its capacity to explore the construction of personal meaning and identity (22). Narrative methods are increasingly acknowledged in primary care research as providing the opportunity to generate insights that cannot be gained from other methods (23).

Narrative research recognises that "the telling of stories is a way, perhaps the most basic way, for humans to make meaning of events in their lives. Stories are used to define who we are, to claim an identity" (22). We collected storied accounts of GPs' experiences of seeing a particular patient whom they and/or the patient (or family member) considered may be experiencing early symptoms of dementia. We were interested in the sequencing and unfolding of events over time, the contextual factors identified as significant in specific cases, and the reasoning behind particular decisions and actions, all aspects of practice that are more easily captured through focusing on concrete rather than abstract perspectives typical of interview methods (24).

We invited all practicing GPs (n = 13) in an academic department of primary care and public health to take part. Seven agreed to participate; the main reason for declining was unavailability within the tight timescale for interviews (restricted by ethical approval and academic timelines). Participants consisted of four female and three male GPs, aged 30 - 65. All had first-hand experience of conveying a diagnosis of dementia, with experience in general practice ranging from 2 – 20 years. Narrative research typically involves a small sample size, the emphasis being on depth rather than breadth and each interview generating a large quantity of data (25).

Before interview, participants were asked to recall and reflect on a particular encounter with a patient as a starting point for the interview. At interview, participants were asked why they had chosen the particular patient/story; to take the interviewer through the particular case including whether and how a diagnosis of dementia was made, and what dilemmas, challenges and learning points were highlighted by this patient's case. The interview was largely informant led, with the interviewer using occasional prompts such as "and then what did you do/decide?" to encourage the flow of a narrative account (26). Interviews were undertaken by SD in the academic department and lasted between 30 minutes – 1 hour. Interviews were audio-recorded and transcribed by SD, resulting in 51 pages (26,757 words) of text for narrative analysis.

SD, JR and DS engaged individually and then collectively in data analysis. We followed the four iterative steps of narrative data analysis identified by Muller: entering the text (reading, sifting and sorting to gain familiarity), sense-making (finding connections, themes, patterns in the data through successive readings and reflection), verifying (searching for alternative explanations, confirmatory and disconfirming data), and representing an account of what has been learned in the research process (22).

RESULTS

> *"The act of diagnosis is really not just a case of gathering a few facts together, or even conducting a mini-mental test and giving a score out of thirty, and doing a range of blood tests and a scan and 'there we have it, there's the diagnosis'. That is the kind of biomedical understanding of how one would make the diagnosis, but in practice, dementia is a very complex problem which impacts on many people, all of whom have a stake in what is going on. What you're presented with is not a patient with a particular score in the test, but a patient living a particular life in particular set of circumstances, with a particular range of family members and a particular range of expectations about what they would like to see in their healthcare management. That is what you're dealing with. And when you look at this bigger context of the patient; the family; the situation; her role as a carer; her role as the secretary of her local […] society…when you see it in that wider context of the lived patient, the notion of making a diagnosis of dementia based on a test score, and so on, starts to seem very [laughs] reductionist and it's not always helpful when you have to manage the realities of the situation. [laughs]"*
>
> *Informant 7*

We will present our findings in three broad, interlinked analytic themes, illustrating these with extracts from the interviews. GPs draw on a range of explanations about the nature of generalism and their identities as generalists as they build their accounts of what constitutes 'timeliness' in the diagnosis of dementia.

Diagnosis as a collective, cumulative contingent process

One of the most striking findings was that diagnosis was not a discrete act that took place at a particular moment in time, but a collective, cumulative, contingent process (27). Despite the policy focus on the urgency of early diagnosis, GPs gave accounts that drew attention to the slow unfolding of *becoming* a person with dementia. None of the doctors' examples involved reaching a diagnosis at a single consultation. The diagnosis would emerge, often over many months, involving not only several consultations but different combinations of patient and family members, and sometimes evaluations in different locations (e.g. surgery and home). GPs talked about "*taking it slowly, slowly*" or "*a softly, softly approach*" or "*chip, chip, chipping away at it*". This involved supporting their patient in the here and now, helping support patients' identity of who they were, helping them manage their relationships with spouses and children. Helping 'the person' (rather than focusing on 'the label'), finding out their concerns and those of their family was the starting point of their decision-making, not necessarily the issue of making a diagnosis: *"I look after you, you are my concern and less of a concern is which label I use for what you have"* (Informant 6).

Box 1 is a GP's account of her experience with a particular patient (whom she described as 'very competent') whom she had looked after for about 15 years. The patient was in her eighties and lived alone, with a son and other relatives nearby.

<< INSERT BOX 1 ABOUT HERE>>

In this account the doctor starts by describing her 'curiosity' when the patient missed appointments, a curiosity contingent on her long experience of looking after this patient, and a keen sense of 'knowing' her. Her curiosity is given further weight when relatives (it later transpires it is her son) call and express concerns. The GP 'eventually' arranges to visit the patient, to 'have a chat with her, do a mini mental test and think about what we needed to do'. There is no sense of urgency in this account, rather attention to working with the patient (she uses the inclusive term 'we') to think about what is needed. She describes this as 'having a chat' suggesting it is a relatively *informal* process at this stage. The GP's account acknowledges implicitly that this 'chat' is actually a potentially difficult conversation, in this case made 'much easier' (emphasised three times) by knowing the patient over many years. The GP makes a thorough assessment of the patient in their home environment. Although this included a mini mental state examination, the GP's narrative focussed primarily on her evaluation of the patient's ability to *manage* in the home. In this particular case, the house is 'absolutely fine', and the GP attributes this to the care of the 'very concerned family'.

The GP then steps back from this particular case, but draws on it to explain that for many patients there is a need to address their fear of losing independence, an issue which several of our GP informants identified: "*what's really important is to be very clear, to take it really quite slowly*". In direct contrast to calls to make the diagnosis as early as possible this GP says she would *never* (in circumstances such as those she uncovered in her evaluation of this particular patient) suggest the memory clinic at this stage "*because you really have to work at that a little bit*". Respecting the patient's wishes, and with due acknowledgement that the patient was neither lacking competence nor at high risk, the GP decides "*you just have to patiently wait*". The important question for this GP reflecting on this particular case was not firming up a diagnosis of dementia, but exploring how the patient is coping and ensuring she is safe.

The GPs in this study emphasised the diagnosis as *process* often using a journeying metaphor, and positioning themselves as 'fellow traveller' in this journey: "*we take this together*" or "*come, we take one step at a time*" and even "*fasten your seatbelts*" - the latter indicating a somewhat unpredictable course. The process of diagnosis is cumulative, a bringing together of different strands over time, and whether a 'formal' diagnosis is reached depends on contingencies such as the wishes of patient and family, the availability or need for local services, and a weighing up of different priorities in the care of the patient as a whole. Consistent across our dataset was the observation that the GPs saw the act of making a formal diagnosis as secondary, and relatively unimportant alongside the many other roles that the

GP played in this situation, such as opening up a conversation, establishing the possibility of future conversations, helping to negotiate the future, ensuring a patient is managing and is safe.

Taking care to ensure that the diagnosis - if it is reached at all - is opportune

The ancient Greeks distinguished between two different concepts of time – chronos (Χρόνος) and kairos (καιρός). Chronos is the most familiar concept of time and refers to chronological time (e.g. clock time, date and year) and notions such as 'early' or 'late' - with their inherent moral implications. Kairos encapsulates the sense of there being an opportune or 'right' time, a time which aligns with a particular set of contingent circumstances (Kairos, in Greek mythology, was the personification of Opportunity). Timeliness was something that GPs defined much more in terms of kairos than chronos. There were several ways in which GPs described their reasoning of what they considered to be appropriate or opportune time. For example, GPs referred to weighing up what help a diagnosis might bring with the negative consequences of a label in terms of patient's identity and sense of independent autonomous self.

In Box 2 a GP describes his dilemma in a situation where both he and the patient's wife suspect the patient has dementia. The dilemma hinges on when the *right* time for reaching a formal diagnosis might be, and on weighing up the potential costs and benefits in a context where he suspects the patient would be ineligible for free social services support as the available services are means-tested ("*Here's a menu, you can pick and choose and pay for it* *yourself*”). The patient (described as “*high functioning*” prior to his recent deterioration) is in his eighties, and his wife whom the GP describes as “*pretty much joined at the hip*” is in her seventies. The GP sets the scene for his account by explaining how the story he hears from the patient when he attends surgery with his wife (*I’m fine…there’s nothing wrong with me”*) is a very different story from that which he hears from the wife when she attends separately. He expands on this in Box 2. The first part of this account bears some similarities to that in Box 1, in that the patient does not himself show interest in pursuing the diagnosis.

<<INSERT BOX 2 ABOUT HERE>>

In this account the doctor is GP to both the patient and his wife, a role which enables unique insight into different perspectives on the patient’s situation, but which also brings its own complexities in terms of managing relationships, balancing the needs of different parties, and recognition that the question of “Who is the patient?” is shifting and contestable at different times and in different contexts. The patient’s wife emerges as the more dominant character in the narrative, at the same time the one on whom the patient is utterly dependent, who ‘does everything’, and yet who may herself be vulnerable. Indeed, much of the narrative is about attending to her needs as the carer, as the GP considers whether and how a formal diagnosis might secure her some additional support. This is a delicate act of negotiation, one which acknowledges on the one hand the need to respect the patient’s autonomy and resist a coercive paternalistic approach and on the other the risk that a poor judgment might result in a ‘crisis’. In the main, the ‘struggle’ here is not with diagnostic uncertainty. The GP refers on several occasions to the patient ‘dementing’, a choice of words which links back to the notion of dementia as a process of becoming - but the struggle is in how to “*get the patient to come around eventually to having an assessment*”. It cannot be rushed, and involves delicate three-way negotiation between the GP and (two) patients.

‘Telling’ or ‘disclosing’ the diagnosis (or recording it in the medical notes) was symbolically a very different act to ‘making’ the diagnosis, and carried a different meaning to simply ‘knowing’ that the patient has dementia. In the example in Box 2, the GP says that both he and the patient’s wife believe the patient is dementing. Likewise, the GP quoted in Box 1 said that she had chosen this particular example as interesting “*because I think I picked up this dementia relatively early* [chronos] *because I knew her very well…I knew there was something odd that she didn’t attend”*, whilst at the same time she has not (yet) made a formal diagnosis but is being ‘patient’ and waiting for the right (kairos) moment. There is a tension maintained between ‘knowing’ and ‘not knowing’ the diagnosis. Towards the end of her interview this GP said “*I don’t think I ever used the term dementia with her…I wouldn’t say that I didn’t give her a diagnosis, but I didn’t give her a label. It’s not the term in itself, it’s what does it mean to this patient?”* (Informant 3)

A different GP gave an account of a patient who attended an appointment with a family member and began by announcing “*Before we go any further, I just want to make it clear that I don’t want you tell me that I’ve got Alzheimer’s*”

(Informant 7). Two consultations later, and with some preliminary investigations completed (a mini mental test score and blood tests) which pointed to a likely diagnosis of dementia, the patient declined an offer of a specialist opinion into her “cognitive difficulties”, the GP noting “*I was sure after two consultations that she was able to make her own decision about whether or not she wanted to pursue being investigated further. She went a little way, but at this point she elected not to take it any further*”.

All these examples bring a very different perspective to the idea that GPs are displaying ‘grim fatalism’ in not necessarily diagnosing early but are making considered judgments about the difference in meaning between the diagnosis *per se* and the disclosure of this diagnosis, between ‘recognition’ and ‘diagnosis’ (18). Precisely what constitutes ‘diagnosis’ is at issue, especially in the context that the ‘symptoms’ are usually those expressed by people *other* than the index patient themselves.

Mol, in her ethnographic study of the diagnosis and treatment of atherosclerosis suggests that in order to make a diagnosis “…*two people are required. A doctor and a patient. The patient must worry or wonder about something and the doctor be willing and able to attend to it*” (page 23) (28). She also describes diagnosis as a composite activity, in which there is a complex inseparable relationship between the detection of disease and the planning of its treatment - the former does not occur without regard to the latter, but neither does it *precede* the latter, rather they are intertwined practices (29). Previous research has shown that the treatments available for dementia are perceived by GPs to be of questionable benefit (11; 16; 17; 20), a finding supported by our study. In none of the stories told by our participants was the 'requirements' Mol asserts as necessary to support a disclosure of diagnosis coming together at the same time and place.

Diagnosis of dementia as constitutive and consequential

Heath has described diagnosis as a doorway between the past and the future. "The process of diagnosis assesses past events and present state and then uses these to predict a future" …"A diagnosis changes the future" (page 63) (30). Similar sentiments are expressed by Rosenberg, who on the subject of disease categories argues "*once articulated, such bureaucratic categories cannot help but exert a variety of substantive effects on individuals and institutional relationships*" (page 254) (27) This coming together of past and future at the moment of disclosure of a diagnosis, and an expressed notion that the *consequentiality* of the diagnosis trumps the *urgency* of diagnosis seemed to hinge primarily on the unpredictability associated with dementia. GPs were cautious about 'predicting the future' and were more concerned to follow what they perceived to be the 'right' course of action in the present. They spoke about "*being with the patient*" and helping patients *"on that day*" whilst at the same time acknowledging the importance of opening up possibilities for future conversations.

Several respondents made (unprompted) reference - explicitly or implicitly - to government policy and national guidance on the diagnosis of dementia. They drew on this rhetorically, not by way of backing up their own decisions on how they had acted in particular situations but to *highlight and contrast it* directly and deliberately with their own decisions *not* to disclose a diagnosis in particular situations, framing this as a careful act of consideration of numerous competing and (sometimes) incommensurable concerns:

> *"You have to be responsive…you have to, all the time, be thinking in a number of prongs as it were. What does the evidence say? What does the patient want?"* (Informant 3)
>
> *"There's got to be a good reason to want to do it, rather than just the, sort of, sake of labeling somebody - which would be great, you know, because then we'd get points for the dementia register. So in that sense there's a huge conflict of interest to just diagnose lot and lots of people and [name of region] has a particular problem with not enough demented people based on the current calculation…so there's lots of incentives to just diagnose people, but there's not much point".* (Informant 2)

This respondent's (Informant 2) reluctance to 'just' diagnose people (the word 'just' appears three times) is embedded within a statement in which he draws attention, with irony, to the conflict of interest presented by certain aspects of current policy - the availability of incentives being not a 'good' or sufficient reason to 'label' somebody.

The extract shown in Box 3 is taken from a narrative interview in which one of our respondents wrestled openly with the range of different possible consequences of disclosing a diagnosis. The GP had seen a Nigerian patient (with her daughter - the patient's carer) and explained how the patient had become "quite mute" after the death of her son, a response which he said he had experienced before in other African patients. The patient's continued withdrawal and memory difficulties might point towards several possible diagnoses, of which dementia was one.

<< INSERT BOX 3 ABOUT HERE>>

As with the example in Box 2, the GP identifies the process of diagnosis as one of negotiation, but extends this to the concept of negotiating not only the diagnosis but ‘a future’. He reflects on the diagnostic label as a warrant to receive future support services which are otherwise more difficult to access, but – in a rhetorical move which likens the gravity of this label (the ‘D’ word) to that of cancer (the “C-word”) – he goes on to describe this label as ‘nasty’ and suggests that it is the restrictions on access to support services that ‘forces’ him to consider attaching such a label, rather than considerations about her rehabilitation needs *per se* (or what he later refers to as ‘supporting the person’). He positions himself as somewhat coerced to take particular courses of action (“*the rehabilitation process forces me*”; “*stupid blood tests*”). His struggle with the extent to which he is both enabling and constraining the patient’s future is captured in his juxtaposition of words in this sentence: “…*it was also opening doors to an enabling perspective to put something under, to put a jar with a lid, with a big ‘D’ written on it, thinking it helps accessing services.*” Diagnosis comes at a cost (the “down side”) to the person - “*labeled*” “*pestered*”, the threat of “*destroying positive outlooks*”. A striking feature of this narrative is the GP’s rich use of metaphor. The patient as “*mute statue*” - imposing and significant, and yet also visibly powerless in her muteness, and himself as the orchestral conductor, working to bring together different concepts within an institutional script that nevertheless imposes constraints on what is possible for him to do.

DISCUSSION

A narrative approach to exploring GPs' perspectives on the meaning of 'timeliness' in the diagnosis of dementia elicited rich data on how this sample of GPs attend to multiple and competing priorities within the context of providing individually tailored care to patients whom they suspect may have dementia. Our study adds to existing research on GPs' views about early diagnosis of dementia by unpacking the 'black box' of 'timeliness', an increasingly used but poorly understood term. Through narrative interviews we were able to capture the contextual and longitudinal, evolving nature of diagnosing a person with dementia, easily occluded by the 'snapshot' picture of practice obtained by conventional interview methods. Of course, narratives are not the 'truth', rather, a perspectival account, but are arguably more authentic than abstract accounts elicited by conventional interview methods (31).

According to the GPs in this study, a timely diagnosis of dementia is a cumulative process, not a one off event, as it is so often assumed. GPs position themselves as fellow travellers in the challenging and unpredictable patient journey of becoming a person with dementia. Timeliness is very different from early diagnosis, what is important is not *when* in terms of chronological time, but 'kairos', the 'right' or opportune time. The GPs in this study did not see themselves as displaying 'grim fatalism' by not necessarily diagnosing early, but as weighing up many complex dilemmas in caring for a patient with early dementia: dilemmas about consent, autonomy, safety, the needs of different parties, access to services, the 'here and now' and the future, and so on. In weighing up the unique factors involved in each individual case, GPs emphasised the ways in which a diagnosis is consequential (32), and how invariably this awareness trumped the *urgency* of diagnosis.

What are the implications of our findings for policy and practice? First, they suggest that the current policy focus on education and training initiatives (5) to improve GPs' awareness of the benefits of early diagnosis may be misguided. Our research supports the recommendations of other researchers that more attention be paid to supporting GPs in the management of complexity and uncertainty, and specifically the dilemmas involved in meeting families' needs for support over long periods (18). Supporting GPs in the provision of timely diagnosis must not be equated with educational attempts at improving rates of early diagnosis.

Second, there is an urgent need to monitor the impact of the NHS Commissioning Board's enhanced service specification for dementia, which links GP practice payments to the number of assessments for dementia it undertakes (7). The BMA has criticised this policy, arguing that: "Practices should never come under pressure to assess patients for dementia who may not ultimately warrant or benefit from assessment" (33). Our findings suggest that such a policy runs the risk of increased rates of *untimely* diagnosis, as GPs come under increasing pressure to practice a form of medicine whereby "the doctor seeks out the patient rather than vice versa" (page 71) (30). The difficult balance that GPs have to negotiate between imagining potential events in the future so that they are identified, managed and experienced in the present (34), and simply being with the patient in the here and now (35) is in danger of being dictated and skewed by policy incentives for early diagnosis.

Thirdly our study indicates the need for researchers to address the critical question of *why* the current policy agenda has so forcibly privileged early diagnosis at the neglect of the more patient-oriented practice of timely diagnosis, despite an increasing number of commentators highlighting the lack of high quality evidence of the benefits of early diagnosis, and the possible dangers of 'overdiagnosis' (8; 9; 11). These and other commentators have raised important questions about the extent to which "big pharma lurks behind those advocating early diagnosis" (11). Certainly, statements such as one in the All Parliamentary report on dementia that "The pharmaceutical company Lundbeck also suggested that terminology should shift from 'early diagnosis' to 'timely diagnosis' in order to shift attention to identifying people who are already in the care system" (2) give a worrying indication of the industry's interests in shaping the policy debate and diagnostic practice.

Mangin et al argue that there is a need to shift our thinking 'beyond diagnosis' and to:

> *"start to value and provide adequate support for the kind of iterative generalist care that focuses more on the person than on the disease entity and the necessary variation this entails. This would place equal value on the art of "not doing" - making complex decisions not to give treatments, not to order tests, and to stop current treatments when in the best interests of the patient."* (36)

Their call is a far cry from the current fixation with early diagnosis of dementia, but encapsulates well the central message to emerge from the GPs in this study: that timeliness is as much about not diagnosing as diagnosing, and about coming to a nuanced, highly contingent and situated judgement about helping the patient “to the right extent, at the right time, with the right aim, and in the right way” (page 43) (Aristotle, quoted in (37)).

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TABLE 1. Arguments for and against the early diagnosis of dementia
(Adapted from (2; 8; 11; 16; 20; 38; 39))

Arguments *for* early diagnostic disclosure	**Arguments *against* early diagnostic disclosure**
Facilitate planning for the future	Risk of causing emotional distress and anxiety; avoiding maleficence
Psychological benefit to person with dementia and / or family members and carers	Inability of person with dementia to understand and / or retain the diagnosis
Maximise opportunity for patient to contribute to the management of their own dementia	No perceived benefits, or perceived costs outweigh perceived benefits
Person's "right to know"	Persons right "not to know"
Maximise treatment possibilities	Lack of robust evidence of improvements to wellbeing from strategies aimed at earlier diagnosis
Obtain access to a second opinion	
Facilitate access to patient support services	Potential risk of 'over-diagnosis'
Patient is already aware of problems and wishes to know	Poor access to necessary specialists and /or support services
	Lack of cure or effective treatments
	Stigma associated with the diagnosis of dementia
	Diversion of resources away from activities of proven value

Box 1

"The first thing that I noticed that was curious about her was that she started not attending appointments, and so that gave me some cause for concern because she was a very meticulous lady and so normally always attended her appointments. And then I had a call from her relatives with some concern about her and so I eventually arranged to go around and have a chat with her, do a mini mental test and think about what we needed to do"

… "I already had an opening: '*You know that your son has phoned me, he's a little bit concerned.*' Uhm and so it's much easier, it's much easier to have that conversation, it's also much easier to have it when you have known somebody over a very long time. And so, um, [hesitation] what I had said to her was that [hesitation] it was a question of exploring with her what *she* thought, whether she was coping alright and whether she thought there was any change in her memory or, or anything, really"

[*The GP explains that when she visited, the patient said that although she sometimes forgets things she was still "getting out and getting things". The patient showed the GP round the house, the GP "wandered" with the patient into the kitchen and looked into the patient's fridge*]…"and just sort of see, you know, what they've got in the house and how they're managing the house. And, of course, because she has a very concerned family, all those things will be *absolutely* fine"

"One of the other problems is that people often, in this situation, particularly somebody who has managed extremely well, is very reluctant to have any support, *very* reluctant to uhm see themselves as giving up any of their independence. Uhm, so it's uhm, I think what's really important is to be very clear, to take it really quite slowly and to make sure that the patient understands that you're going along several tracks at once. You know, let's check that you're not anaemic, that you haven't got a thyroid problem, you know, those kinds of things. And, certainly, I would never, in these kinds of circumstances suggest a visit from the memory clinic people at the first stage, because you really have to work at that a little bit. Um, so, that was fine and so, because we've known each for quite a long time, there wasn't really a problem about talking about this. And, as I recall, she really wasn't very keen for anybody to come in initially and there was no reason for me to consider that she was *highly* at risk and so, you know, in those circumstances, if somebody is basically refusing referral, unless they haven't got competence, you know, you just have to patiently wait…With her it is very much not a question of giving her a diagnosis of dementia, but exploring with her, in a much more holistic way, how she is able to cope both mentally and physically. And the fact that over time, these things change, and getting her to acknowledge that she may need additional support and what kind of form that kind of help can take.

(Informant 3)

Box 2

"We're pretty sure he's dementing…When [his wife] comes along for *her* problems, because she's the main carer and you'll come round to the thing 'Oh yeah, you know Mr So and So, my husband, he's doing this, he's doing that, what can we do?'…. I said to her, 'Look, you know, I'm perfectly happy to send the memory clinic people around, do you think he'd agree?' And she went 'Oh, he'd probably lose it, he'd probably scream and shout and chuck them out the door' and stuff…so, that's created a dilemma in the sense that we *do* need his consent, because we can't *assume* just because he's dementing that he has no ability to make any consent at all…she is the main carer, she looks after his medication, she sorts out the food, she sorts out the finances, she pretty much does everything…So anyway I've given her the contact details to the Alzheimer's society and then that's it. 'If you want any support, then maybe you can start leaving the leaflets around the house' or things like that. But the real *challenge* here is to get people to come around eventually to having an assessment."

[The GP goes on to describe some of the services available locally. Later he returns to this particular example]

"If they're in either a state of denial or have limited insight, it might be more difficult because you're not really pushing against an open door…It's a difficult one because, I mean, in a way we could always insist that people were seen and say 'Look, you know, I think it's really, really important'. I mean, the sort of, extreme of that would potentially be being a form of bullying because you can, you can literally say 'oh, I really do think you should see them and I don't care what you think, because I think you're dementing and you have to be seen and making the diagnosis is very important for you' which, you know, actually, sounds massively paternalistic and it *is…"*

"I think it is a negotiation as to what one can do. So, you can always negotiate harder and I certainly could have negotiated harder [in this particular case] but I would prefer - I mean, maybe it's a personal style - I certainly would prefer that, you know, they come, or eventually come round to your view. Now, the catch with that is that sometimes what happens is you get a crisis. You could say 'Well, you could have intervened earlier'. Yeah! But that then would have been counter to providing him with any particular form of, you know, autonomy. So, that's a constant struggle, just knowing, 'could I have done that?' …it's a constant struggle. I mean, it's difficult to know, because how would I know anyway whether it was a better or worse decision?"

(Informant 2)

Box 3

GP: “So I thought I must be very, very careful in establishing a diagnostic label. I think I’m…however it’s important to access certain services. If you say you need help for your condition then the help is only available with a certain label, so I cannot say “um, yeh I think she has got some rehabilitation needs and her carer has carer strain”. So I thought if I want to build up a support structure I have to put it under the ‘D’ label, so kind of, the rehabilitation process forces me to attach a label on her forehead. A nasty label. Dementia.”

[the GP goes on to explain how he tentatively proceeded to make some steps towards establishing a diagnosis]

I had some work up to do, to send stupid blood tests for syphilis. I thought ‘Come On, it’s 19th century’ but yes, the memory clinic wants that. X-ray, this and that. I explored what she thinks about the consequences of diagnosis. I think it’s a little bit like counseling for a HIV test. You need to, kind of, be a step ahead before and say “What do you understand dementia is?”

Researcher: “And what did she respond?”

GP: The woman herself didn’t understand. She was like a mute statue next to her daughter who did the negotiation. And I said “It can have very bleak consequences, but not necessarily.” But there was already a run up to it. It didn’t…there were symptoms, there were concerns, the daughter already worked part-time not full-time. So in a way it was also opening doors to an enabling perspective to put something under, to put a jar with a lid, with a big ‘D’ written on it, thinking it helps accessing services. The down side is you are then on the list in our practice. You’re pestered with regular health checks and this and that. You are labeled.

Researcher: Any advice you feel is helpful for other healthcare professionals to keep in mind?

GP: To think about the consequences of diagnosis. Think about what, how it relates to supporting the person and especially thinking about the care structure in place….I’m very, very careful about um, destroying positive outlooks on life with the diagnostic label. Especially if there is not much which can be done….I orchestrated, like a conductor, bringing different concepts in and negotiating, negotiating a future.

(Informant 6)

Research ethics approval

Research ethics approval was granted by Queen Mary, University of London Research Ethics Committee (reference 1071)

Contributorship statement

SD had the idea for the research study. All authors contributed to the design of the study. SD completed all data collection and transcription. All authors contributed to the analysis of the data. All authors contributed to the preparation of the manuscript and its earlier drafts. DS is the guarantor for the paper.

Data Sharing

Anonymised transcripts of interviews are available on request from the corresponding author.

Transparency declaration

DS (guarantor) affirms that the manuscript is an honest, accurate and transparent account of the study being reported and that no important aspects of the study have been omitted.

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'Timely' Diagnosis of Dementia: What does it mean? A narrative analysis of GPs' accounts

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‘TIMELY’ DIAGNOSIS OF DEMENTIA: WHAT DOES IT MEAN? A NARRATIVE ANALYSIS OF GPs’ ACCOUNTS

Saadia Aziz Dhedhi* (corresponding author)
Medical Student

Deborah Swinglehurst* (guarantor)
NIHR Senior Clinical Lecturer

Jill Russell*
Senior Lecturer in Health Policy and Evaluation

* Centre for Primary Care and Public Health, Barts and The London School of Medicine and Dentistry, Queen Mary, University of London, 58 Turner Street, London E1 2AB

Correspondence to:
T: +44 7958 508 293
E: ha09131@qmul.ac.uk

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ABSTRACT

Objective To explore general practitioners' perspectives on the meaning of 'timeliness' in dementia diagnosis.

Design Narrative interview study.

Setting UK academic department of primary care.

Participants Seven practicing GPs with experience of conveying a diagnosis of dementia.

Methods GPs' narrative commentaries of encounters with patients with suspected dementia were audio-recorded and transcribed resulting in 51 pages of text (26,757 words). Detailed narrative analysis of doctors' accounts was conducted.

Results Diagnosis of dementia is a complex medical and social practice. Clinicians attend to multiple competing priorities whilst providing individually tailored patient care, against a background of shifting political and institutional concerns. Interviewees drew on a range of explanations about the nature of generalism to legitimise their claims about whether and how they made a diagnosis, constructing their accounts of what constituted 'timeliness'. Three interlinked analytic themes were identified: 1) Diagnosis as a collective, cumulative, contingent process 2) Taking care to ensure that diagnosis - if reached at all - is *opportune* 3) Diagnosis of dementia as constitutive or consequential, but also a diagnosis whose consequences are unpredictable.

Conclusions Timeliness in the diagnosis of dementia involves balancing a range of judgements and is not experienced in terms of simple chronological notions of time. Reluctance or failure to make a diagnosis on a particular occasion does not necessarily point to GPs' lack of awareness of current

policies, nor to a set of training needs, but commonly reflects this range of nuanced balancing judgements, often negotiated with patients and their families with detailed attention to a particular context. In the case of dementia, the taken-for-granted benefits of early diagnosis cannot be assumed, but need to be 'worked through' on an individual case-by-case basis. GPs tend to value 'rightness' of time over concerns about 'early' diagnosis.

Article Summary

Strengths and limitations of this study

- Adopts a novel methodological approach, based on narrative analysis, to explore the meaning of 'timely' diagnosis of dementia in general practice, addressing an important gap in the research literature.
- The methodological approach adopted generates insights that cannot be gained from more conventional approaches to interviews and analysis.
- The study findings have important implications for practice and policy, suggesting that current policy efforts to increase rates of 'timely' diagnosis runs the risk of increased rates of 'untimely' diagnosis
- Prioritises depth of analysis over breadth, each interview generating a large amount of data for analysis.
- The interview participants may not be typical of all GPs in how they approach the diagnosis of dementia

INTRODUCTION

The diagnosis of dementia is high on the health policy agenda. The last few years have seen a proliferation of reports and calls for action for the early diagnosis of dementia, nationally and internationally (1-4). In March 2012 David Cameron, launched the 'Prime Minister's Challenge on Dementia' (5), announcing a commitment to address the 'shockingly low' diagnosis rates for dementia in England (6) (only 42% of people with dementia have a formal diagnosis, according to the Department of Health (5)). In 2013 the NHS Commissioning Board published plans for a new enhanced service "for take up by GPs as part of the GP contract for 2013/14 to reward practices for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia" (7).

An increasingly widespread view is that 'timely diagnosis' is a more appropriate concept than 'early diagnosis'. 'Timely' implies a more person-centred approach and benefit to the patient, and does not tie the diagnosis to any particular disease stage (8). Some commentators distinguish between 'timely', meaning at the right time for the particular patient in the specific circumstances, and 'early' diagnosis in the chronological sense (9; 10). More often the two terms are used interchangeably, disregarding their different meanings, and with the emphasis firmly on *early* diagnosis. Policy documents invariably present the benefits of early diagnosis as axiomatic, although in the medical press and research papers the possible harms associated with 'premature diagnosis', new diagnostic categories of 'pre-dementia' and overdiagnosis of the frail elderly are widely voiced (8; 9; 11; 12) . Table 1 identifies the common arguments for and against the early diagnosis of dementia.

<INSERT TABLE 1 ABOUT HERE>

Largely missing from the policy debate is empirical evidence of how doctors in the front line of diagnosis, typically GPs, construct, interpret and manage the concept of timeliness. In media reports GPs are invariably portrayed as barriers to diagnosis, and accused of “grim fatalism” (6). Implicit in much research on this topic is a ‘deficit model’ of GP behaviour and attitudes; a common assumption is that GPs are not necessarily acting in the best interests of their patients in how they approach diagnosis. The research focus then turns to uncovering the ‘constraints’ and ‘barriers’ to earlier diagnosis (13-16), often resulting in proposals for educational interventions to improve GPs’ rates of diagnosis.

A growing body of research is emerging which highlights that GPs, far from acting out of ignorance, consider the diagnostic process as a nuanced weighing up of many different factors, varying between patients depending on the specifics of each case (17-21). Furthermore, these studies highlight that diagnosis is not a single event, but an evolving process. Whilst such studies have contributed significantly to our understanding of GPs’ experiences of diagnosing dementia and factors impacting on early diagnosis, none has considered specifically the much used but poorly understood concept of timeliness.

Existing research suggests it is time to study GP practice in relation to diagnosing dementia from a fresh perspective, one that does not take a deficit model as its starting point, and critically, one that captures its contextual and evolving nature. This paper presents findings of an in-depth study of UK GPs which aimed to explore, from a narrative perspective, how the notion of 'timeliness' is constructed in practice, and how GPs account for the decisions they make about the diagnosis of dementia.

METHODS

This study was undertaken as part of an intercalated BSc Global Health dissertation between November 2012 and May 2013. It received ethical approval from the Queen Mary University of London Research Ethics Committee (reference 1071). We were interested in exploring the nature of disclosure in the diagnosis of dementia, and in particular what a 'timely' diagnosis means to GPs and how GPs represent themselves as "agents acting in life worlds of moral complexity" (22). We chose a narrative methodology because of its capacity to explore the construction of personal meaning and identity (23). Narrative methods are increasingly acknowledged in primary care research as providing the opportunity to generate insights that cannot be gained from other methods (24).

Narrative research recognises that "the telling of stories is a way, perhaps the most basic way, for humans to make meaning of events in their lives. Stories are used to define who we are, to claim an identity" (23). We collected storied accounts of GPs' experiences of seeing a particular patient whom they and/or the patient (or family member) considered may be experiencing early symptoms of dementia. We were interested in the sequencing and unfolding of events over time, the contextual factors identified as significant in specific cases, and the reasoning behind particular decisions and actions, all aspects of practice that are more easily captured through focusing on concrete rather than abstract perspectives typical of interview methods (25).

We invited all practicing GPs (n = 13) in an academic department of primary care and public health to take part. Seven agreed to participate; the main reason for declining was unavailability within the tight timescale for interviews (restricted by ethical approval and academic timelines). Participants consisted of four female and three male GPs, aged 30 - 65. All had first-hand experience of conveying a diagnosis of dementia, with experience in general practice ranging from 2 – 20 years. Narrative research typically involves a small sample size, the emphasis being on depth rather than breadth and each interview generating a large quantity of data (26).

Before interview, participants were asked to recall and reflect on a particular encounter with a patient as a starting point for the interview. At interview, participants were asked why they had chosen the particular patient/story; to take the interviewer through the particular case including whether and how a diagnosis of dementia was made, and what dilemmas, challenges and learning points were highlighted by this patient's case. The interview was largely informant led, with the interviewer using occasional prompts such as "and then what did you do/decide?" to encourage the flow of a narrative account (27). The topic guide shown in Figure 1 outlines broad areas of enquiry; additional areas were explored, following the narrative threads pursued by participants (28). Interviews were undertaken by SD in the academic department and lasted between 30 minutes – 1 hour. Interviews were audio-recorded and transcribed by SD, resulting in 51 pages (26,757 words) of text for narrative analysis.

<<INSERT FIGURE 1 ABOUT HERE>>

SD, JR and DS engaged individually and then collectively in data analysis. We followed the four iterative steps of narrative data analysis identified by Muller: entering the text (reading, sifting and sorting to gain familiarity), sense-making (finding connections, themes, patterns in the data through successive readings and reflection), verifying (searching for alternative explanations, confirmatory and disconfirming data), and representing an account of what has been learned in the research process (23). The analytic themes reported in the next section are those that emerged from this iterative approach to analysis of participants' accounts.

RESULTS

> *"The act of diagnosis is really not just a case of gathering a few facts together, or even conducting a mini-mental test and giving a score out of thirty, and doing a range of blood tests and a scan and 'there we*

> *have it, there's the diagnosis'. That is the kind of biomedical understanding of how one would make the diagnosis, but in practice, dementia is a very complex problem which impacts on many people, all of whom have a stake in what is going on. What you're presented with is not a patient with a particular score in the test, but a patient living a particular life in particular set of circumstances, with a particular range of family members and a particular range of expectations about what they would like to see in their healthcare management. That is what you're dealing with. And when you look at this bigger context of the patient; the family; the situation; her role as a carer; her role as the secretary of her local […] society…when you see it in that wider context of the lived patient, the notion of making a diagnosis of dementia based on a test score, and so on, starts to seem very [laughs] reductionist and it's not always helpful when you have to manage the realities of the situation. [laughs]"*
>
> *Informant 7*

We will present our findings in three broad, interlinked analytic themes, illustrating these with extracts from the interviews. GPs draw on a range of explanations about the nature of generalism and their identities as generalists as they build their accounts of what constitutes 'timeliness' in the diagnosis of dementia.

Diagnosis as a collective, cumulative contingent process

One of the most striking findings was that diagnosis was not a discrete act that took place at a particular moment in time, but a collective, cumulative, contingent process (29). Despite the policy focus on the urgency of early diagnosis, GPs gave accounts that drew attention to the slow unfolding of *becoming* a person with dementia. None of the doctors' examples involved reaching a diagnosis at a single consultation. The diagnosis would emerge, often over many months, involving not only several consultations but different combinations of patient and family members, and sometimes evaluations in different locations (e.g. surgery and home). GPs talked about "*taking it slowly, slowly*" or "*a softly, softly approach*" or "*chip, chip, chipping away at it*". This involved supporting their patient in the here and now, helping support patients' identity of who they were, helping them manage their relationships with spouses and children. Helping 'the person' (rather than focusing on 'the label'), finding out their concerns and those of their family was the starting point of their decision-making, not necessarily the issue of making a diagnosis: *"I look after you, you are my concern and less of a concern is which label I use for what you have"* (Informant 6).

Box 1 is a GP's account of her experience with a particular patient (whom she described as 'very competent') whom she had looked after for about 15 years. The patient was in her eighties and lived alone, with a son and other relatives nearby.

<< INSERT BOX 1 ABOUT HERE>>

In this account the doctor starts by describing her 'curiosity' when the patient missed appointments, a curiosity contingent on her long experience of looking after this patient, and a keen sense of 'knowing' her. Her curiosity is given further weight when relatives (it later transpires it is her son) call and express concerns. The GP 'eventually' arranges to visit the patient, to 'have a chat with her, do a mini mental test and think about what we needed to do'. There is no sense of urgency in this account, rather attention to working with the patient (she uses the inclusive term 'we') to think about what is needed. She describes this as 'having a chat' suggesting it is a relatively *informal* process at this stage. The GP's account acknowledges implicitly that this 'chat' is actually a potentially difficult conversation, in this case made 'much easier' (emphasised three times) by knowing the patient over many years. The GP makes a thorough assessment of the patient in their home environment. Although this included a mini mental state examination, the GP's narrative focussed primarily on her evaluation of the patient's ability to *manage* in the home. In this particular case, the house is 'absolutely fine', and the GP attributes this to the care of the 'very concerned family'.

The GP then steps back from this particular case, but draws on it to explain that for many patients there is a need to address their fear of losing independence, an issue which several of our GP informants identified: "*what's really important is to be very clear, to take it really quite slowly*". In direct contrast to calls to make the diagnosis as early as possible this GP says she would *never* (in circumstances such as those she uncovered in her evaluation of this particular patient) suggest the memory clinic at this stage "*because you really have to work at that a little bit*". Respecting the patient's wishes, and with due acknowledgement that the patient was neither lacking competence nor at high risk, the GP decides "*you just have to patiently wait*". The important question for this GP reflecting on this particular case was not firming up a diagnosis of dementia, but exploring how the patient is coping and ensuring she is safe.

The GPs in this study emphasised the diagnosis as *process* often using a journeying metaphor, and positioning themselves as 'fellow traveller' in this journey: “*we take this together*” or “*come, we take one step at a time*” and even “*fasten your seatbelts*” - the latter indicating a somewhat unpredictable course. The process of diagnosis is cumulative, a bringing together of different strands over time, and whether a ‘formal’ diagnosis is reached depends on contingencies such as the wishes of patient and family, the availability or need for local services, and a weighing up of different priorities in the care of the patient as a whole. Consistent across our dataset was the observation that the GPs saw the act of making a formal diagnosis as secondary, and relatively unimportant alongside the many other roles that the GP played in this situation, such as opening up a conversation, establishing the possibility of future conversations, helping to negotiate the future, ensuring a patient is managing and is safe.

Taking care to ensure that the diagnosis - if it is reached at all - is opportune

The ancient Greeks distinguished between two different concepts of time – chronos (Χρόνος) and kairos (καιρός). Chronos is the most familiar concept of time and refers to chronological time (e.g. clock time, date and year) and notions such as ‘early’ or ‘late’ - with their inherent moral implications. Kairos encapsulates the sense of there being an opportune or ‘right’ time, a time which aligns with a particular set of contingent circumstances (Kairos, in Greek mythology, was the personification of Opportunity). Timeliness was something that GPs defined much more in terms of kairos than chronos. There were several ways in which GPs described their reasoning of what they considered to be appropriate or opportune time. For example, GPs referred to weighing up what help a diagnosis might bring with the negative consequences of a label in terms of patient's identity and sense of independent autonomous self.

In Box 2 a GP describes his dilemma in a situation where both he and the patient's wife suspect the patient has dementia. The dilemma hinges on when the *right* time for reaching a formal diagnosis might be, and on weighing up the potential costs and benefits in a context where he suspects the patient would be ineligible for free social services support as the available services are means-tested ("*Here's a menu, you can pick and choose and pay for it yourself*"). The patient (described as "*high functioning*" prior to his recent deterioration) is in his eighties, and his wife whom the GP describes as "*pretty much joined at the hip*" is in her seventies. The GP sets the scene for his account by explaining how the story he hears from the patient when he attends surgery with his wife (*I'm fine…there's nothing wrong with me"*) is a very different story from that which he hears from the wife when she attends separately. He expands on this in Box 2. The first part of this account bears some similarities to that in Box 1, in that the patient does not himself show interest in pursuing the diagnosis.

<<INSERT BOX 2 ABOUT HERE>>

In this account the doctor is GP to both the patient and his wife, a role which enables unique insight into different perspectives on the patient's situation, but which also brings its own complexities in terms of managing relationships, balancing the needs of different parties, and recognition that the question of

"Who is the patient?" is shifting and contestable at different times and in different contexts. The patient's wife emerges as the more dominant character in the narrative, at the same time the one on whom the patient is utterly dependent, who 'does everything', and yet who may herself be vulnerable. Indeed, much of the narrative is about attending to her needs as the carer, as the GP considers whether and how a formal diagnosis might secure her some additional support. This is a delicate act of negotiation, one which acknowledges on the one hand the need to respect the patient's autonomy and resist a coercive paternalistic approach and on the other the risk that a poor judgment might result in a 'crisis'. In the main, the 'struggle' here is not with diagnostic uncertainty. The GP refers on several occasions to the patient 'dementing', a choice of words which links back to the notion of dementia as a process of becoming - but the struggle is in how to "*get the patient to come around eventually to having an assessment*". It cannot be rushed, and involves delicate three-way negotiation between the GP and (two) patients.

'Telling' or 'disclosing' the diagnosis (or recording it in the medical notes) was symbolically a very different act to 'making' the diagnosis, and carried a different meaning to simply 'knowing' that the patient has dementia. In the example in Box 2, the GP says that both he and the patient's wife believe the patient is dementing. Likewise, the GP quoted in Box 1 said that she had chosen this particular example as interesting "*because I think I picked up this dementia relatively early* [chronos] *because I knew her very well…I knew there was something odd that she didn't attend",* whilst at the same time she has not (yet) made a formal diagnosis but is being 'patient' and waiting for the right (kairos) moment. There is a tension maintained between ‘knowing’ and ‘not knowing’ the diagnosis. Towards the end of her interview this GP said “*I don’t think I ever used the term dementia with her…I wouldn’t say that I didn’t give her a diagnosis, but I didn’t give her a label. It’s not the term in itself, it’s what does it mean to this patient?”* (Informant 3)

A different GP gave an account of a patient who attended an appointment with a family member and began by announcing “*Before we go any further, I just want to make it clear that I don’t want you tell me that I’ve got Alzheimer’s*” (Informant 7). Two consultations later, and with some preliminary investigations completed (a mini mental test score and blood tests) which pointed to a likely diagnosis of dementia, the patient declined an offer of a specialist opinion into her “cognitive difficulties”, the GP noting “*I was sure after two consultations that she was able to make her own decision about whether or not she wanted to pursue being investigated further. She went a little way, but at this point she elected not to take it any further*”.

All these examples bring a very different perspective to the idea that GPs are displaying ‘grim fatalism’ in not necessarily diagnosing early but are making considered judgments about the difference in meaning between the diagnosis *per se* and the disclosure of this diagnosis, between ‘recognition’ and ‘diagnosis’ (19). Precisely what constitutes ‘diagnosis’ is at issue, especially in the context that the ‘symptoms’ are usually those expressed by people *other* than the index patient themselves.

Mol, in her ethnographic study of the diagnosis and treatment of atherosclerosis suggests that in order to make a diagnosis "…*two people are required. A doctor and a patient. The patient must worry or wonder about something and the doctor be willing and able to attend to it*" (page 23) (30). She also describes diagnosis as a composite activity, in which there is a complex inseparable relationship between the detection of disease and the planning of its treatment - the former does not occur without regard to the latter, but neither does it *precede* the latter, rather they are intertwined practices (31). Previous research has shown that the treatments available for dementia are perceived by GPs to be of questionable benefit (11; 17; 18; 21), a finding supported by our study. In none of the stories told by our participants were the 'requirements' Mol asserts as necessary to support a disclosure of diagnosis coming together at the same time and place.

Diagnosis of dementia as constitutive and consequential

Heath has described diagnosis as a doorway between the past and the future. "The process of diagnosis assesses past events and present state and then uses these to predict a future" …"A diagnosis changes the future" (page 63) (32). Similar sentiments are expressed by Rosenberg, who on the subject of disease categories argues "*once articulated, such bureaucratic categories cannot help but exert a variety of substantive effects on individuals and institutional relationships*" (page 254) (29) This coming together of past and future at the moment of disclosure of a diagnosis, and an expressed notion that the *consequentiality* of the diagnosis trumps the *urgency* of diagnosis seemed to hinge primarily on the unpredictability associated with dementia. GPs were cautious about ‘predicting the future’ and were more concerned to follow what they perceived to be the ‘right’ course of action in the present. They spoke about “*being with the patient*” and helping patients *“on that day*” whilst at the same time acknowledging the importance of opening up possibilities for future conversations.

Several respondents made (unprompted) reference - explicitly or implicitly - to government policy and national guidance on the diagnosis of dementia. They drew on this rhetorically, not by way of backing up their own decisions on how they had acted in particular situations but to *highlight and contrast it* directly and deliberately with their own decisions *not* to disclose a diagnosis in particular situations, framing this as a careful act of consideration of numerous competing and (sometimes) incommensurable concerns:

> *“You have to be responsive…you have to, all the time, be thinking in a number of prongs as it were. What does the evidence say? What does the patient want?”* (Informant 3)
>
> *“There’s got to be a good reason to want to do it, rather than just the, sort of, sake of labeling somebody - which would be great, you know, because then we’d get points for the dementia register. So in that sense there’s a huge conflict of interest to just diagnose lots and lots of people and [name of region] has a particular problem with not enough demented people based on the current calculation…so there’s lots of incentives to just diagnose people, but there’s not much point”.* (Informant 2)

This respondent’s (Informant 2) reluctance to ‘just’ diagnose people (the word ‘just’ appears three times) is embedded within a statement in which he draws attention, with irony, to the conflict of interest presented by certain aspects of current policy - the availability of incentives being not a ‘good’ or sufficient reason to ‘label’ somebody.

The extract shown in Box 3 is taken from a narrative interview in which one of our respondents wrestled openly with the range of different possible consequences of disclosing a diagnosis. The GP had seen a Nigerian patient (with her daughter - the patient's carer) and explained how the patient had become "quite mute" after the death of her son, a response which he said he had experienced before in other African patients. The patient's continued withdrawal and memory difficulties might point towards several possible diagnoses, of which dementia was one.

<< INSERT BOX 3 ABOUT HERE>>

As with the example in Box 2, the GP identifies the process of diagnosis as one of negotiation, but extends this to the concept of negotiating not only the diagnosis but 'a future'. He reflects on the diagnostic label as a warrant to receive future support services which are otherwise more difficult to access, but – in a rhetorical move which likens the gravity of this label (the 'D' word) to that of cancer (the "C-word") – he goes on to describe this label as 'nasty' and suggests that it is the restrictions on access to support services that 'forces' him to consider attaching such a label, rather than considerations about her rehabilitation needs *per se* (or what he later refers to as 'supporting the person'). He positions himself as somewhat coerced to take particular courses of action ("*the rehabilitation process forces me*"; "*stupid blood tests*"). His struggle with the extent to which he is both enabling and constraining the patient's future is captured in his juxtaposition of words in this sentence: "…*it* *was also opening doors to an enabling perspective to put something under, to put a jar with a lid, with a big 'D' written on it, thinking it helps accessing services.*" Diagnosis comes at a cost (the "down side") to the person - "*labeled*" "*pestered*", the threat of "*destroying positive outlooks*". A striking feature of this narrative is the GP's rich use of metaphor. The patient as "*mute statue*" - imposing and significant, and yet also visibly powerless in her muteness, and himself as the orchestral conductor, working to bring together different concepts within an institutional script that nevertheless imposes constraints on what is possible for him to do.

DISCUSSION

A narrative approach to exploring GPs' perspectives on the meaning of 'timeliness' in the diagnosis of dementia elicited rich data on how this sample of GPs attend to multiple and competing priorities within the context of providing individually tailored care to patients whom they suspect may have dementia. Our study adds to existing research on GPs' views about early diagnosis of dementia by unpacking the 'black box' of 'timeliness', an increasingly used but poorly understood term. Through narrative interviews we were able to capture the contextual and longitudinal, evolving nature of diagnosing a person with dementia, easily occluded by the 'snapshot' picture of practice obtained by conventional interview methods. Of course, narratives are not the 'truth', rather, a perspectival account, but are arguably more authentic than abstract accounts elicited by conventional interview methods (33).

According to the GPs in this study, a timely diagnosis of dementia is a cumulative process, not a one off event, as it is so often assumed. GPs position themselves as fellow travellers in the challenging and unpredictable patient journey of becoming a person with dementia. Timeliness is very different from early diagnosis; what is important is not *when* in terms of chronological time, but ‘kairos’, the ‘right’ or opportune time. The GPs in this study did not see themselves as displaying ‘grim fatalism’ by not necessarily diagnosing early, but as weighing up many complex dilemmas in caring for a patient with early dementia: dilemmas about consent, autonomy, safety, the needs of different parties, access to services, the ‘here and now’ and the future, and so on. In weighing up the unique factors involved in each individual case, GPs emphasised the ways in which a diagnosis is consequential (34), and how invariably this awareness trumped the *urgency* of diagnosis.

The GPs in this small study were all practicing GPs with academic appointments and it is possible that their approach to the diagnosis of dementia might not be typical of all GPs. However concerns about generalisability are not central to narrative research, in which the focus is on what can be learned from in-depth study of the *particular* narrative that can extend and challenge conventional understandings. There was no evidence in the data to suggest that the interviewees adopted a ‘teaching’ stance in their interviews with the student researcher. Indeed several participants raised unprompted criticisms of current clinical guidance and policy, contrasting aspects of these with their own decisions on how to act in particular situations;

this would seem unusual in a more conventional undergraduate teaching scenario.

What are the implications of our findings for policy and practice? First, they suggest that the current policy focus on education and training initiatives (5) to improve GPs' awareness of the benefits of early diagnosis may be misguided. Our research supports the recommendations of other researchers that more attention be paid to supporting GPs in the management of complexity and uncertainty, and specifically the dilemmas involved in meeting families' needs for support over long periods (19). Supporting GPs in the provision of timely diagnosis must not be equated with educational attempts at improving rates of early diagnosis.

Second, there is an urgent need to monitor the impact of the NHS Commissioning Board's enhanced service specification for dementia, which links GP practice payments to the number of assessments for dementia it undertakes (7). The BMA has criticised this policy, arguing that: "Practices should never come under pressure to assess patients for dementia who may not ultimately warrant or benefit from assessment" (35). Our findings suggest that such a policy runs the risk of increased rates of *untimely* diagnosis, as GPs come under increasing pressure to practice a form of medicine whereby "the doctor seeks out the patient rather than vice versa" (page 71) (32). The difficult balance that GPs have to negotiate between imagining potential events in the future so that they are identified, managed and experienced in the present (36), and simply being with the patient in the here and now (37) is in danger of being dictated and skewed by policy incentives for early diagnosis.

Thirdly our study indicates the need for researchers to address the critical question of *why* the current policy agenda has so forcibly privileged early diagnosis at the neglect of the more patient-oriented practice of timely diagnosis, despite an increasing number of commentators highlighting the lack of high quality evidence of the benefits of early diagnosis, and the possible dangers of 'overdiagnosis' (8; 9; 11). These and other commentators have raised important questions about the extent to which "big pharma lurks behind those advocating early diagnosis" (11). Certainly, statements such as one in the All Parliamentary report on dementia that "The pharmaceutical company Lundbeck also suggested that terminology should shift from 'early diagnosis' to 'timely diagnosis' in order to shift attention to identifying people who are already in the care system" (2) give a worrying indication of the industry's interests in shaping the policy debate and diagnostic practice.

Mangin et al argue that there is a need to shift our thinking 'beyond diagnosis' and to:

> *"start to value and provide adequate support for the kind of iterative generalist care that focuses more on the person than on the disease entity and the necessary variation this entails. This would place equal value on the art of "not doing" - making complex decisions not to give treatments, not to order tests, and to stop current treatments when in the best interests of the patient." (38)*

Their call is a far cry from the current fixation with early diagnosis of dementia, but encapsulates well the central message to emerge from the GPs in this study: that timeliness is as much about not diagnosing as diagnosing, and about coming to a nuanced, highly contingent and situated judgement about helping the patient “to the right extent, at the right time, with the right aim, and in the right way” (page 43) (Aristotle, quoted in (39)).

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Research ethics approval

Research ethics approval was granted by Queen Mary, University of London Research Ethics Committee (reference 1071)

Contributorship statement

SD had the idea for the research study. All authors contributed to the design of the study. SD completed all data collection and transcription. All authors contributed to the analysis of the data. All authors contributed to the preparation of the manuscript and its earlier drafts. DS is the guarantor for the paper.

Data Sharing

Anonymised transcripts of interviews are available on request from the corresponding author.

Transparency declaration

DS (guarantor) affirms that the manuscript is an honest, accurate and transparent account of the study being reported and that no important aspects of the study have been omitted.

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TABLE 1. Arguments for and against the early diagnosis of dementia
(Adapted from (2; 8; 11; 17; 21; 40; 41))

Arguments *for* early diagnostic disclosure	Arguments *against* early diagnostic disclosure
Facilitate planning for the future	Risk of causing emotional distress and anxiety; avoiding maleficence
Psychological benefit to person with dementia and / or family members and carers	Inability of person with dementia to understand and / or retain the diagnosis
Maximise opportunity for patient to contribute to the management of their own dementia	No perceived benefits, or perceived costs outweigh perceived benefits
Person’s “right to know”	Persons right “not to know”
Maximise treatment possibilities	Lack of robust evidence of improvements to wellbeing from strategies aimed at earlier diagnosis
Obtain access to a second opinion	
Facilitate access to patient support services	Potential risk of ‘over-diagnosis’
Patient is already aware of problems and wishes to know	Poor access to necessary specialists and /or support services
	Lack of cure or effective treatments
	Stigma associated with the diagnosis of dementia
	Diversion of resources away from activities of proven value

Box 1

"The first thing that I noticed that was curious about her was that she started not attending appointments, and so that gave me some cause for concern because she was a very meticulous lady and so normally always attended her appointments. And then I had a call from her relatives with some concern about her and so I eventually arranged to go around and have a chat with her, do a mini mental test and think about what we needed to do"

… "I already had an opening: '*You know that your son has phoned me, he's a little bit concerned.*' Uhm and so it's much easier, it's much easier to have that conversation, it's also much easier to have it when you have known somebody over a very long time. And so, um, [hesitation] what I had said to her was that [hesitation] it was a question of exploring with her what *she* thought, whether she was coping alright and whether she thought there was any change in her memory or, or anything, really"

[*The GP explains that when she visited, the patient said that although she sometimes forgets things she was still "getting out and getting things". The patient showed the GP round the house, the GP "wandered" with the patient into the kitchen and looked into the patient's fridge*]…"and just sort of see, you know, what they've got in the house and how they're managing the house. And, of course, because she has a very concerned family, all those things will be *absolutely* fine"

"One of the other problems is that people often, in this situation, particularly somebody who has managed extremely well, is very reluctant to have any support, *very* reluctant to uhm see themselves as giving up any of their independence. Uhm, so it's uhm, I think what's really important is to be very clear, to take it really quite slowly and to make sure that the patient understands that you're going along several tracks at once. You know, let's check that you're not anaemic, that you haven't got a thyroid problem, you know, those kinds of things. And, certainly, I would never, in these kinds of circumstances suggest a visit from the memory clinic people at the first stage, because you really have to work at that a little bit. Um, so, that was fine and so, because we've known each for quite a long time, there wasn't really a problem about talking about this. And, as I recall, she really wasn't very keen for anybody to come in initially and there was no reason for me to consider that she was *highly* at risk and so, you know, in those circumstances, if somebody is basically refusing referral, unless they haven't got competence, you know, you just have to patiently wait…With her it is very much not a question of giving her a diagnosis of dementia, but exploring with her, in a much more holistic way, how she is able to cope both mentally and physically. And the fact that over time, these things change, and getting her to acknowledge that she may need additional support and what kind of form that kind of help can take.

(Informant 3)

Box 2

"We're pretty sure he's dementing…When [his wife] comes along for *her* problems, because she's the main carer and you'll come round to the thing 'Oh yeah, you know Mr So and So, my husband, he's doing this, he's doing that, what can we do?'…. I said to her, 'Look, you know, I'm perfectly happy to send the memory clinic people around, do you think he'd agree?' And she went 'Oh, he'd probably lose it, he'd probably scream and shout and chuck them out the door' and stuff…so, that's created a dilemma in the sense that we *do* need his consent, because we can't *assume* just because he's dementing that he has no ability to make any consent at all…she is the main carer, she looks after his medication, she sorts out the food, she sorts out the finances, she pretty much does everything…So anyway I've given her the contact details to the Alzheimer's society and then that's it. 'If you want any support, then maybe you can start leaving the leaflets around the house' or things like that. But the real *challenge* here is to get people to come around eventually to having an assessment."

[The GP goes on to describe some of the services available locally. Later he returns to this particular example]

"If they're in either a state of denial or have limited insight, it might be more difficult because you're not really pushing against an open door…It's a difficult one because, I mean, in a way we could always insist that people were seen and say 'Look, you know, I think it's really, really important'. I mean, the sort of, extreme of that would potentially be being a form of bullying because you can, you can literally say 'oh, I really do think you should see them and I don't care what you think, because I think you're dementing and you have to be seen and making the diagnosis is very important for you' which, you know, actually, sounds massively paternalistic and it *is…"*

"I think it is a negotiation as to what one can do. So, you can always negotiate harder and I certainly could have negotiated harder [in this particular case] but I would prefer - I mean, maybe it's a personal style - I certainly would prefer that, you know, they come, or eventually come round to your view. Now, the catch with that is that sometimes what happens is you get a crisis. You could say 'Well, you could have intervened earlier'. Yeah! But that then would have been counter to providing him with any particular form of, you know, autonomy. So, that's a constant struggle, just knowing, 'could I have done that?' …it's a constant struggle. I mean, it's difficult to know, because how would I know anyway whether it was a better or worse decision?"

(Informant 2)

Box 3

GP: “So I thought I must be very, very careful in establishing a diagnostic label. I think I’m…however it’s important to access certain services. If you say you need help for your condition then the help is only available with a certain label, so I cannot say “um, yeh I think she has got some rehabilitation needs and her carer has carer strain”. So I thought if I want to build up a support structure I have to put it under the ‘D’ label, so kind of, the rehabilitation process forces me to attach a label on her forehead. A nasty label. Dementia.”

[the GP goes on to explain how he tentatively proceeded to make some steps towards establishing a diagnosis]

I had some work up to do, to send stupid blood tests for syphilis. I thought ‘Come On, it’s 19th century’ but yes, the memory clinic wants that. X-ray, this and that. I explored what she thinks about the consequences of diagnosis. I think it’s a little bit like counseling for a HIV test. You need to, kind of, be a step ahead before and say “What do you understand dementia is?”

Researcher: “And what did she respond?”

GP: The woman herself didn’t understand. She was like a mute statue next to her daughter who did the negotiation. And I said “It can have very bleak consequences, but not necessarily.” But there was already a run up to it. It didn’t…there were symptoms, there were concerns, the daughter already worked part-time not full-time. So in a way it was also opening doors to an enabling perspective to put something under, to put a jar with a lid, with a big ‘D’ written on it, thinking it helps accessing services. The down side is you are then on the list in our practice. You’re pestered with regular health checks and this and that. You are labeled.

Researcher: Any advice you feel is helpful for other healthcare professionals to keep in mind?

GP: To think about the consequences of diagnosis. Think about what, how it relates to supporting the person and especially thinking about the care structure in place….I’m very, very careful about um, destroying positive outlooks on life with the diagnostic label. Especially if there is not much which can be done….I orchestrated, like a conductor, bringing different concepts in and negotiating, negotiating a future.

(Informant 6)

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'TIMELY' DIAGNOSIS OF DEMENTIA: WHAT DOES IT MEAN? A NARRATIVE ANALYSIS OF GPs' ACCOUNTS

Saadia Aziz Dhedhi* (corresponding author)
Medical Student

Deborah Swinglehurst* (guarantor)
NIHR Senior Clinical Lecturer

Jill Russell*
Senior Lecturer in Health Policy and Evaluation

* Centre for Primary Care and Public Health, Barts and The London School of Medicine and Dentistry, Queen Mary, University of London, 58 Turner Street, London E1 2AB

Correspondence to:
T: +44 7958 508 293
E: ha09131@qmul.ac.uk

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Key words: dementia, diagnosis, disclosure, general practitioner, narrative

ABSTRACT

Objective To explore general practitioners' perspectives on the meaning of 'timeliness' in dementia diagnosis.

Design Narrative interview study.

Setting UK academic department of primary care.

Participants Seven practicing GPs with experience of conveying a diagnosis of dementia.

Methods GPs' narrative commentaries of encounters with patients with suspected dementia were audio-recorded and transcribed resulting in 51 pages of text (26,757 words). Detailed narrative analysis of doctors' accounts was conducted.

Results Diagnosis of dementia is a complex medical and social practice. Clinicians attend to multiple competing priorities whilst providing individually tailored patient care, against a background of shifting political and institutional concerns. Interviewees drew on a range of explanations about the nature of generalism to legitimise their claims about whether and how they made a diagnosis, constructing their accounts of what constituted 'timeliness'. Three interlinked analytic themes were identified: 1) Diagnosis as a collective, cumulative, contingent process 2) Taking care to ensure that diagnosis - if reached at all - is *opportune* 3) Diagnosis of dementia as constitutive or consequential, but also a diagnosis whose consequences are unpredictable.

Conclusions Timeliness in the diagnosis of dementia involves balancing a range of judgements and is not experienced in terms of simple chronological notions of time. Reluctance or failure to make a diagnosis on a particular

occasion does not necessarily point to GPs' lack of awareness of current policies, nor to a set of training needs, but commonly reflects this range of nuanced balancing judgements, often negotiated with patients and their families with detailed attention to a particular context. In the case of dementia, the taken-for-granted benefits of early diagnosis cannot be assumed, but need to be 'worked through' on an individual case-by-case basis. GPs tend to value 'rightness' of time over concerns about 'early' diagnosis.

Article Summary

Strengths and limitations of this study

- Adopts a novel methodological approach, based on narrative analysis, to explore the meaning of 'timely' diagnosis of dementia in general practice, addressing an important gap in the research literature.
- The methodological approach adopted generates insights that cannot be gained from more conventional approaches to interviews and analysis.
- The study findings have important implications for practice and policy, suggesting that current policy efforts to increase rates of 'timely' diagnosis runs the risk of increased rates of 'untimely' diagnosis
- Prioritises depth of analysis over breadth, each interview generating a large amount of data for analysis.
- The interview participants may not be typical of all GPs in how they approach the diagnosis of dementia

INTRODUCTION

The diagnosis of dementia is high on the health policy agenda. The last few years have seen a proliferation of reports and calls for action for the early diagnosis of dementia, nationally and internationally (1-4). In March 2012 David Cameron, launched the ‘Prime Minister’s Challenge on Dementia’ (5), announcing a commitment to address the ‘shockingly low’ diagnosis rates for dementia in England (6) (only 42% of people with dementia have a formal diagnosis, according to the Department of Health (5)). In 2013 the NHS Commissioning Board published plans for a new enhanced service “for take up by GPs as part of the GP contract for 2013/14 to reward practices for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia” (7).

An increasingly widespread view is that ‘timely diagnosis’ is a more appropriate concept than ‘early diagnosis’. ‘Timely’ implies a more person-centred approach and benefit to the patient, and does not tie the diagnosis to any particular disease stage (8). Some commentators distinguish between ‘timely’, meaning at the right time for the particular patient in the specific circumstances, and ‘early’ diagnosis in the chronological sense (9; 10). More often the two terms are used interchangeably, disregarding their different meanings, and with the emphasis firmly on *early* diagnosis. Policy documents invariably present the benefits of early diagnosis as axiomatic, although in the medical press and research papers the possible harms associated with ~~of~~ ‘premature diagnosis’, new diagnostic categories of ‘pre-dementia’ ~~–~~and overdiagnosis of the frail elderly are ~~is~~ widely voiced (8; 9; 11; 12) . Table 1 identifies the common arguments for and against the early diagnosis of dementia.

<INSERT TABLE 1 ABOUT HERE>

Largely missing from the policy debate is empirical evidence of how doctors in the front line of diagnosis, typically GPs, construct, interpret and manage the concept of timeliness. In media reports GPs are invariably portrayed as barriers to diagnosis, and accused of "grim fatalism" (6). Implicit in much research on this topic is a 'deficit model' of GP behaviour and attitudes; a common assumption is that GPs are not necessarily acting in the best interests of their patients in how they approach diagnosis. The research focus then turns to uncovering the 'constraints' and 'barriers' to earlier diagnosis (13-16), often resulting in proposals for educational interventions to improve GPs' rates of diagnosis.

A growing body of research is emerging which highlights that GPs, far from acting out of ignorance, consider the diagnostic process as a nuanced weighing up of many different factors, varying between patients depending on the specifics of each case (17-21). Furthermore, these studies highlight that diagnosis is not a single event, but an evolving process. Whilst such studies have contributed significantly to our understanding of GPs' experiences of diagnosing dementia and factors impacting on early diagnosis, none has considered specifically the much used but poorly understood concept of timeliness.

Existing research suggests it is time to study GP practice in relation to diagnosing dementia from a fresh perspective, one that does not take a deficit model as its starting point, and critically, one that captures its contextual and evolving nature. This paper presents findings of an in-depth study of UK GPs which aimed to explore, from a narrative perspective, how the notion of 'timeliness' is constructed in practice, and how GPs account for the decisions they make about the diagnosis of dementia.

METHODS

This study was undertaken as part of an intercalated BSc Global Health dissertation between November 2012 and May 2013. It received ethical approval from the Queen Mary University of London Research Ethics Committee (reference 1071). We were interested in exploring the nature of disclosure in the diagnosis of dementia, and in particular ~~We were interested in finding out~~ what a 'timely' diagnosis means to GPs and how GPs represent themselves as "agents acting in life worlds of moral complexity" (22). We chose a narrative methodology because of its capacity to explore the construction of personal meaning and identity (23). Narrative methods are increasingly acknowledged in primary care research as providing the opportunity to generate insights that cannot be gained from other methods (24).

Narrative research recognises that “the telling of stories is a way, perhaps the most basic way, for humans to make meaning of events in their lives. Stories are used to define who we are, to claim an identity” (23). We collected storied accounts of GPs’ experiences of seeing a particular patient whom they and/or the patient (or family member) considered may be experiencing early symptoms of dementia. We were interested in the sequencing and unfolding of events over time, the contextual factors identified as significant in specific cases, and the reasoning behind particular decisions and actions, all aspects of practice that are more easily captured through focusing on concrete rather than abstract perspectives typical of interview methods (25).

We invited all practicing GPs (n = 13) in an academic department of primary care and public health to take part. Seven agreed to participate; the main reason for declining was unavailability within the tight timescale for interviews (restricted by ethical approval and academic timelines). Participants consisted of four female and three male GPs, aged 30 - 65. All had first-hand experience of conveying a diagnosis of dementia, with experience in general practice ranging from 2 – 20 years. Narrative research typically involves a small sample size, the emphasis being on depth rather than breadth and each interview generating a large quantity of data (26).

Before interview, participants were asked to recall and reflect on a particular encounter with a patient as a starting point for the interview. At interview, participants were asked why they had chosen the particular patient/story; to take the interviewer through the particular case including whether and how a diagnosis of dementia was made, and what dilemmas, challenges and learning points were highlighted by this patient's case. The interview was largely informant led, with the interviewer using occasional prompts such as "and then what did you do/decide?" to encourage the flow of a narrative account (27). The topic guide shown in Figure 1 outlines broad areas of enquiry; additional areas were explored, following the narrative threads pursued by participants (28). Interviews were undertaken by SD in the academic department and lasted between 30 minutes – 1 hour. Interviews were audio-recorded and transcribed by SD, resulting in 51 pages (26,757 words) of text for narrative analysis.

<<INSERT FIGURE 1 ABOUT HERE>>

SD, JR and DS engaged individually and then collectively in data analysis. We followed the four iterative steps of narrative data analysis identified by Muller: entering the text (reading, sifting and sorting to gain familiarity), sense-making (finding connections, themes, patterns in the data through successive readings and reflection), verifying (searching for alternative explanations, confirmatory and disconfirming data), and representing an account of what has been learned in the research process (23). The analytic themes reported in the next section are those that emerged from this iterative approach to analysis of participants' accounts.

RESULTS

> *"The act of diagnosis is really not just a case of gathering a few facts together, or even conducting a mini-mental test and giving a score out of thirty, and doing a range of blood tests and a scan and 'there we have it, there's the diagnosis'. That is the kind of biomedical understanding of how one would make the diagnosis, but in practice, dementia is a very complex problem which impacts on many people, all of whom have a stake in what is going on. What you're presented with is not a patient with a particular score in the test, but a patient living a particular life in particular set of circumstances, with a particular range of family members and a particular range of expectations about what they would like to see in their healthcare management. That is what you're dealing with. And when you look at this bigger context of the patient; the family; the situation; her role as a carer; her role as the secretary of her local […] society…when you see it in that wider context of the lived patient, the notion of making a diagnosis of dementia based on a test score, and so on, starts to seem very [laughs] reductionist and it's not always helpful when you have to manage the realities of the situation. [laughs]"*
>
> *Informant 7*

We will present our findings in three broad, interlinked analytic themes, illustrating these with extracts from the interviews. GPs draw on a range of explanations about the nature of generalism and their identities as generalists as they build their accounts of what constitutes 'timeliness' in the diagnosis of dementia.

Diagnosis as a collective, cumulative contingent process

One of the most striking findings was that diagnosis was not a discrete act that took place at a particular moment in time, but a collective, cumulative, contingent process (29). Despite the policy focus on the urgency of early diagnosis, GPs gave accounts that drew attention to the slow unfolding of *becoming* a person with dementia. None of the doctors' examples involved reaching a diagnosis at a single consultation. The diagnosis would emerge, often over many months, involving not only several consultations but different combinations of patient and family members, and sometimes evaluations in different locations (e.g. surgery and home). GPs talked about "*taking it slowly, slowly*" or "*a softly, softly approach*" or "*chip, chip, chipping away at it*". This involved supporting their patient in the here and now, helping support patients' identity of who they were, helping them manage their relationships with spouses and children. Helping 'the person' (rather than focusing on 'the label'), finding out their concerns and those of their family was the starting point of their decision-making, not necessarily the issue of making a diagnosis: *"I look after you, you are my concern and less of a concern is which label I use for what you have"* (Informant 6).

Box 1 is a GP's account of her experience with a particular patient (whom she described as 'very competent') whom she had looked after for about 15 years. The patient was in her eighties and lived alone, with a son and other relatives nearby.

<< INSERT BOX 1 ABOUT HERE>>

In this account the doctor starts by describing her 'curiosity' when the patient missed appointments, a curiosity contingent on her long experience of looking after this patient, and a keen sense of 'knowing' her. Her curiosity is given further weight when relatives (it later transpires it is her son) call and express concerns. The GP 'eventually' arranges to visit the patient, to 'have a chat with her, do a mini mental test and think about what we needed to do'. There is no sense of urgency in this account, rather attention to working with the patient (she uses the inclusive term 'we') to think about what is needed. She describes this as 'having a chat' suggesting it is a relatively *informal* process at this stage. The GP's account acknowledges implicitly that this 'chat' is actually a potentially difficult conversation, in this case made 'much easier' (emphasised three times) by knowing the patient over many years. The GP makes a thorough assessment of the patient in their home environment. Although this included a mini mental state examination, the GP's narrative focussed primarily on her evaluation of the patient's ability to *manage* in the home. In this particular case, the house is 'absolutely fine', and the GP attributes this to the care of the 'very concerned family'.

The GP then steps back from this particular case, but draws on it to explain that for many patients there is a need to address their fear of losing independence, an issue which several of our GP informants identified: "*what's really important is to be very clear, to take it really quite slowly*". In direct contrast to calls to make the diagnosis as early as possible this GP says she would *never* (in circumstances such as those she uncovered in her evaluation of this particular patient) suggest the memory clinic at this stage "*because you really have to work at that a little bit*". Respecting the patient's wishes, and with due acknowledgement that the patient was neither lacking competence nor at high risk, the GP decides "*you just have to patiently wait*". The important question for this GP reflecting on this particular case was not firming up a diagnosis of dementia, but exploring how the patient is coping and ensuring she is safe.

The GPs in this study emphasised the diagnosis as *process* often using a journeying metaphor, and positioning themselves as 'fellow traveller' in this journey: "*we take this together*" or "*come, we take one step at a time*" and even "*fasten your seatbelts*" - the latter indicating a somewhat unpredictable course. The process of diagnosis is cumulative, a bringing together of different strands over time, and whether a 'formal' diagnosis is reached depends on contingencies such as the wishes of patient and family, the availability or need for local services, and a weighing up of different priorities in the care of the patient as a whole. Consistent across our dataset was the observation that the GPs saw the act of making a formal diagnosis as secondary, and relatively unimportant alongside the many other roles that the GP played in this situation, such as opening up a conversation, establishing the possibility of future conversations, helping to negotiate the future, ensuring a patient is managing and is safe.

Taking care to ensure that the diagnosis - if it is reached at all - is opportune

The ancient Greeks distinguished between two different concepts of time – chronos (Χρόνος) and kairos (καιρός). Chronos is the most familiar concept of time and refers to chronological time (e.g. clock time, date and year) and notions such as 'early' or 'late' - with their inherent moral implications. Kairos encapsulates the sense of there being an opportune or 'right' time, a time which aligns with a particular set of contingent circumstances (Kairos, in

Greek mythology, was the personification of Opportunity). Timeliness was something that GPs defined much more in terms of kairos than chronos. There were several ways in which GPs described their reasoning of what they considered to be appropriate or opportune time. For example, GPs referred to weighing up what help a diagnosis might bring with the negative consequences of a label in terms of patient's identity and sense of independent autonomous self.

In Box 2 a GP describes his dilemma in a situation where both he and the patient's wife suspect the patient has dementia. The dilemma hinges on when the *right* time for reaching a formal diagnosis might be, and on weighing up the potential costs and benefits in a context where he suspects the patient would be ineligible for free social services support as the available services are means-tested ("*Here's a menu, you can pick and choose and pay for it yourself*"). The patient (described as "*high functioning*" prior to his recent deterioration) is in his eighties, and his wife whom the GP describes as "*pretty much joined at the hip*" is in her seventies. The GP sets the scene for his account by explaining how the story he hears from the patient when he attends surgery with his wife (*I'm fine…there's nothing wrong with me"*) is a very different story from that which he hears from the wife when she attends separately. He expands on this in Box 2. The first part of this account bears some similarities to that in Box 1, in that the patient does not himself show interest in pursuing the diagnosis.

<<INSERT BOX 2 ABOUT HERE>>

In this account the doctor is GP to both the patient and his wife, a role which enables unique insight into different perspectives on the patient's situation, but which also brings its own complexities in terms of managing relationships, balancing the needs of different parties, and recognition that the question of "Who is the patient?" is shifting and contestable at different times and in different contexts. The patient's wife emerges as the more dominant character in the narrative, at the same time the one on whom the patient is utterly dependent, who 'does everything', and yet who may herself be vulnerable. Indeed, much of the narrative is about attending to her needs as the carer, as the GP considers whether and how a formal diagnosis might secure her some additional support. This is a delicate act of negotiation, one which acknowledges on the one hand the need to respect the patient's autonomy and resist a coercive paternalistic approach and on the other the risk that a poor judgment might result in a 'crisis'. In the main, the 'struggle' here is not with diagnostic uncertainty. The GP refers on several occasions to the patient 'dementing', a choice of words which links back to the notion of dementia as a process of becoming - but the struggle is in how to "*get the patient to come around eventually to having an assessment*". It cannot be rushed, and involves delicate three-way negotiation between the GP and (two) patients.

'Telling' or 'disclosing' the diagnosis (or recording it in the medical notes) was symbolically a very different act to 'making' the diagnosis, and carried a different meaning to simply 'knowing' that the patient has dementia. In the example in Box 2, the GP says that both he and the patient's wife believe the patient is dementing. Likewise, the GP quoted in Box 1 said that she had chosen this particular example as interesting “*because I think I picked up this dementia relatively early* [chronos] *because I knew her very well…I knew there was something odd that she didn’t attend”,* whilst at the same time she has not (yet) made a formal diagnosis but is being ‘patient’ and waiting for the right (kairos) moment. There is a tension maintained between ‘knowing’ and ‘not knowing’ the diagnosis. Towards the end of her interview this GP said “*I don’t think I ever used the term dementia with her…I wouldn’t say that I didn’t give her a diagnosis, but I didn’t give her a label. It’s not the term in itself, it’s what does it mean to this patient?”* (Informant 3)

A different GP gave an account of a patient who attended an appointment with a family member and began by announcing “*Before we go any further, I just want to make it clear that I don’t want you tell me that I’ve got Alzheimer’s*” (Informant 7). Two consultations later, and with some preliminary investigations completed (a mini mental test score and blood tests) which pointed to a likely diagnosis of dementia, the patient declined an offer of a specialist opinion into her “cognitive difficulties”, the GP noting “*I was sure after two consultations that she was able to make her own decision about whether or not she wanted to pursue being investigated further. She went a little way, but at this point she elected not to take it any further*”.

All these examples bring a very different perspective to the idea that GPs are displaying ‘grim fatalism’ in not necessarily diagnosing early but are making considered judgments about the difference in meaning between the diagnosis *per se* and the disclosure of this diagnosis, between ‘recognition’ and ‘diagnosis’ (19). Precisely what constitutes ‘diagnosis’ is at issue, especially in the context that the ‘symptoms’ are usually those expressed by people *other* than the index patient themselves.

Mol, in her ethnographic study of the diagnosis and treatment of atherosclerosis suggests that in order to make a diagnosis “…*two people are required. A doctor and a patient. The patient must worry or wonder about something and the doctor be willing and able to attend to it*” (page 23) (30). She also describes diagnosis as a composite activity, in which there is a complex inseparable relationship between the detection of disease and the planning of its treatment - the former does not occur without regard to the latter, but neither does it *precede* the latter, rather they are intertwined practices (31). Previous research has shown that the treatments available for dementia are perceived by GPs to be of questionable benefit (11; 17; 18; 21), a finding supported by our study. In none of the stories told by our participants ~~was~~ were the ‘requirements’ Mol asserts as necessary to support a disclosure of diagnosis coming together at the same time and place.

Diagnosis of dementia as constitutive and consequential

Heath has described diagnosis as a doorway between the past and the future. "The process of diagnosis assesses past events and present state and then uses these to predict a future" …"A diagnosis changes the future" (page 63) (32). Similar sentiments are expressed by Rosenberg, who on the subject of disease categories argues “*once articulated, such bureaucratic* *categories cannot help but exert a variety of substantive effects on individuals and institutional relationships*" (page 254) (29) This coming together of past and future at the moment of disclosure of a diagnosis, and an expressed notion that the *consequentiality* of the diagnosis trumps the *urgency* of diagnosis seemed to hinge primarily on the unpredictability associated with dementia. GPs were cautious about 'predicting the future' and were more concerned to follow what they perceived to be the 'right' course of action in the present. They spoke about "*being with the patient*" and helping patients *"on that day*" whilst at the same time acknowledging the importance of opening up possibilities for future conversations.

Several respondents made (unprompted) reference - explicitly or implicitly - to government policy and national guidance on the diagnosis of dementia. They drew on this rhetorically, not by way of backing up their own decisions on how they had acted in particular situations but to *highlight and contrast it* directly and deliberately with their own decisions *not* to disclose a diagnosis in particular situations, framing this as a careful act of consideration of numerous competing and (sometimes) incommensurable concerns:

> *"You have to be responsive…you have to, all the time, be thinking in a number of prongs as it were. What does the evidence say? What does the patient want?"* (Informant 3)
>
> *"There's got to be a good reason to want to do it, rather than just the, sort of, sake of labeling somebody - which would be great, you know, because then we'd get points for the dementia register. So in that sense there's a huge conflict of interest to just diagnose lots and lots of people and [name of region] has a particular problem with not enough demented people based on the current calculation…so there's lots of incentives to just diagnose people, but there's not much point".* (Informant 2)

This respondent's (Informant 2) reluctance to 'just' diagnose people (the word 'just' appears three times) is embedded within a statement in which he draws attention, with irony, to the conflict of interest presented by certain aspects of current policy - the availability of incentives being not a 'good' or sufficient reason to 'label' somebody.

The extract shown in Box 3 is taken from a narrative interview in which one of our respondents wrestled openly with the range of different possible consequences of disclosing a diagnosis. The GP had seen a Nigerian patient (with her daughter - the patient's carer) and explained how the patient had become "quite mute" after the death of her son, a response which he said he had experienced before in other African patients. The patient's continued withdrawal and memory difficulties might point towards several possible diagnoses, of which dementia was one.

<< INSERT BOX 3 ABOUT HERE>>

As with the example in Box 2, the GP identifies the process of diagnosis as one of negotiation, but extends this to the concept of negotiating not only the diagnosis but 'a future'. He reflects on the diagnostic label as a warrant to receive future support services which are otherwise more difficult to access, but – in a rhetorical move which likens the gravity of this label (the 'D' word) to that of cancer (the "C-word") – he goes on to describe this label as 'nasty' and suggests that it is the restrictions on access to support services that 'forces' him to consider attaching such a label, rather than considerations about her rehabilitation needs *per se* (or what he later refers to as ‘supporting the person’). He positions himself as somewhat coerced to take particular courses of action (“*the rehabilitation process forces me*”; “*stupid blood tests*”). His struggle with the extent to which he is both enabling and constraining the patient’s future is captured in his juxtaposition of words in this sentence: “…*it was also opening doors to an enabling perspective to put something under, to put a jar with a lid, with a big ‘D’ written on it, thinking it helps accessing services.*” Diagnosis comes at a cost (the “down side”) to the person - “*labeled*” “*pestered*”, the threat of “*destroying positive outlooks*”. A striking feature of this narrative is the GP’s rich use of metaphor. The patient as “*mute statue*” - imposing and significant, and yet also visibly powerless in her muteness, and himself as the orchestral conductor, working to bring together different concepts within an institutional script that nevertheless imposes constraints on what is possible for him to do.

DISCUSSION

A narrative approach to exploring GPs’ perspectives on the meaning of ‘timeliness’ in the diagnosis of dementia elicited rich data on how this sample of GPs attend to multiple and competing priorities within the context of providing individually tailored care to patients whom they suspect may have dementia. Our study adds to existing research on GPs’ views about early diagnosis of dementia by unpacking the ‘black box’ of ‘timeliness’, an increasingly used but poorly understood term. Through narrative interviews we were able to capture the contextual and longitudinal, evolving nature of diagnosing a person with dementia, easily occluded by the ‘snapshot’ picture of practice obtained by conventional interview methods. Of course, narratives are not the ‘truth’, rather, a perspectival account, but are arguably more authentic than abstract accounts elicited by conventional interview methods (33).

According to the GPs in this study, a timely diagnosis of dementia is a cumulative process, not a one off event, as it is so often assumed. GPs position themselves as fellow travellers in the challenging and unpredictable patient journey of becoming a person with dementia. Timeliness is very different from early diagnosis~~,~~; what is important is not *when* in terms of chronological time, but ‘kairos’, the ‘right’ or opportune time. The GPs in this study did not see themselves as displaying ‘grim fatalism’ by not necessarily diagnosing early, but as weighing up many complex dilemmas in caring for a patient with early dementia: dilemmas about consent, autonomy, safety, the needs of different parties, access to services, the ‘here and now’ and the future, and so on. In weighing up the unique factors involved in each individual case, GPs emphasised the ways in which a diagnosis is consequential (34), and how invariably this awareness trumped the *urgency* of diagnosis.

The GPs in this small study were all practicing GPs with academic appointments and it is possible that their approach to the diagnosis of dementia might not be typical of all GPs. However concerns about generalisability are not central to narrative research, in which the focus is on what can be learned from in-depth study of the *particular* narrative that can

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extend and challenge conventional understandings. There was no evidence in the data to suggest that the interviewees adopted a ‘teaching’ stance in their interviews with the student researcher. Indeed several participants raised unprompted criticisms of current clinical guidance and policy, contrasting aspects of these with their own decisions on how to act in particular situations; this would seem unusual in a more conventional undergraduate teaching scenario.

What are the implications of our findings for policy and practice? First, they suggest that the current policy focus on education and training initiatives (5) to improve GPs’ awareness of the benefits of early diagnosis may be misguided. Our research supports the recommendations of other researchers that more attention be paid to supporting GPs in the management of complexity and uncertainty, and specifically the dilemmas involved in meeting families’ needs for support over long periods (19). Supporting GPs in the provision of timely diagnosis must not be equated with educational attempts at improving rates of early diagnosis.

Second, there is an urgent need to monitor the impact of the NHS Commissioning Board’s enhanced service specification for dementia, which links GP practice payments to the number of assessments for dementia it undertakes (7). The BMA has criticised this policy, arguing that: “Practices should never come under pressure to assess patients for dementia who may not ultimately warrant or benefit from assessment” (35). Our findings suggest that such a policy runs the risk of increased rates of *untimely* diagnosis, as

GPs come under increasing pressure to practice a form of medicine whereby “the doctor seeks out the patient rather than vice versa” (page 71) (32). The difficult balance that GPs have to negotiate between imagining potential events in the future so that they are identified, managed and experienced in the present (36), and simply being with the patient in the here and now (37) is in danger of being dictated and skewed by policy incentives for early diagnosis.

Thirdly our study indicates the need for researchers to address the critical question of *why* the current policy agenda has so forcibly privileged early diagnosis at the neglect of the more patient-oriented practice of timely diagnosis, despite an increasing number of commentators highlighting the lack of high quality evidence of the benefits of early diagnosis, and the possible dangers of ‘overdiagnosis’ (8; 9; 11). These and other commentators have raised important questions about the extent to which “big pharma lurks behind those advocating early diagnosis” (11). Certainly, statements such as one in the All Parliamentary report on dementia that “The pharmaceutical company Lundbeck also suggested that terminology should shift from ‘early diagnosis’ to ‘timely diagnosis’ in order to shift attention to identifying people who are already in the care system” (2) give a worrying indication of the industry’s interests in shaping the policy debate and diagnostic practice.

Mangin et al argue that there is a need to shift our thinking ‘beyond diagnosis’ and to:

> *“start to value and provide adequate support for the kind of iterative generalist care that focuses more on the person than on the disease*

> *entity and the necessary variation this entails. This would place equal value on the art of "not doing" - making complex decisions not to give treatments, not to order tests, and to stop current treatments when in the best interests of the patient."* (38)

Their call is a far cry from the current fixation with early diagnosis of dementia, but encapsulates well the central message to emerge from the GPs in this study: that timeliness is as much about not diagnosing as diagnosing, and about coming to a nuanced, highly contingent and situated judgement about helping the patient "to the right extent, at the right time, with the right aim, and in the right way" (page 43) (Aristotle, quoted in (39)).

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TABLE 1. Arguments for and against the early diagnosis of dementia
(Adapted from (2; 8; 11; 17; 21; 40; 41))

Arguments *for* early diagnostic disclosure	Arguments *against* early diagnostic disclosure
Facilitate planning for the future	Risk of causing emotional distress and anxiety; avoiding maleficence
Psychological benefit to person with dementia and / or family members and carers	Inability of person with dementia to understand and / or retain the diagnosis
Maximise opportunity for patient to contribute to the management of their own dementia	No perceived benefits, or perceived costs outweigh perceived benefits
Person's "right to know"	Persons right "not to know"
Maximise treatment possibilities Obtain access to a second opinion	Lack of robust evidence of improvements to wellbeing from strategies aimed at earlier diagnosis
Facilitate access to patient support services	Potential risk of 'over-diagnosis'
Patient is already aware of problems and wishes to know	Poor access to necessary specialists and /or support services
	Lack of cure or effective treatments
	Stigma associated with the diagnosis of dementia
	Diversion of resources away from activities of proven value

Figure 1. Topic Guide for narrative interviews

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- Can you tell me about a particular encounter you've had with a patient with dementia, especially around diagnosing dementia or conveying a diagnosis of dementia?

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- *(if relevant)* How did you go about telling this particular patient that they had a diagnosis of dementia?

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- How did you overcome any particular issues or challenges that arose in this case?
- How well do you think you dealt with the challenges that arose in this case? Do you feel you could have done anything differently?
- Why did you choose this particular patient / story?
- What are the learning points for *you* from this particular experience?

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- Do you identify any learning points for *other* health care professionals?
- How important do you think it is to make a diagnosis of dementia?
- *(prompt)* Are there any particular factors you consider when making a diagnosis of dementia?

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- Are there other important points you feel we have missed out?

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Box 1

"The first thing that I noticed that was curious about her was that she started not attending appointments, and so that gave me some cause for concern because she was a very meticulous lady and so normally always attended her appointments. And then I had a call from her relatives with some concern about her and so I eventually arranged to go around and have a chat with her, do a mini mental test and think about what we needed to do"

… "I already had an opening: '*You know that your son has phoned me, he's a little bit concerned.*' Uhm and so it's much easier, it's much easier to have that conversation, it's also much easier to have it when you have known somebody over a very long time. And so, um, [hesitation] what I had said to her was that [hesitation] it was a question of exploring with her what *she* thought, whether she was coping alright and whether she thought there was any change in her memory or, or anything, really"

[*The GP explains that when she visited, the patient said that although she sometimes forgets things she was still "getting out and getting things". The patient showed the GP round the house, the GP "wandered" with the patient into the kitchen and looked into the patient's fridge*]…"and just sort of see, you know, what they've got in the house and how they're managing the house. And, of course, because she has a very concerned family, all those things will be *absolutely* fine"

"One of the other problems is that people often, in this situation, particularly somebody who has managed extremely well, is very reluctant to have any support, *very* reluctant to uhm see themselves as giving up any of their independence. Uhm, so it's uhm, I think what's really important is to be very clear, to take it really quite slowly and to make sure that the patient understands that you're going along several tracks at once. You know, let's check that you're not anaemic, that you haven't got a thyroid problem, you know, those kinds of things. And, certainly, I would never, in these kinds of circumstances suggest a visit from the memory clinic people at the first stage, because you really have to work at that a little bit. Um, so, that was fine and so, because we've known each for quite a long time, there wasn't really a problem about talking about this. And, as I recall, she really wasn't very keen for anybody to come in initially and there was no reason for me to consider that she was *highly* at risk and so, you know, in those circumstances, if somebody is basically refusing referral, unless they haven't got competence, you know, you just have to patiently wait…With her it is very much not a question of giving her a diagnosis of dementia, but exploring with her, in a much more holistic way, how she is able to cope both mentally and physically. And the fact that over time, these things change, and getting her to acknowledge that she may need additional support and what kind of form that kind of help can take.

(Informant 3)

Box 2

"We're pretty sure he's dementing…When [his wife] comes along for *her* problems, because she's the main carer and you'll come round to the thing 'Oh yeah, you know Mr So and So, my husband, he's doing this, he's doing that, what can we do?'…. I said to her, 'Look, you know, I'm perfectly happy to send the memory clinic people around, do you think he'd agree?' And she went 'Oh, he'd probably lose it, he'd probably scream and shout and chuck them out the door' and stuff…so, that's created a dilemma in the sense that we *do* need his consent, because we can't *assume* just because he's dementing that he has no ability to make any consent at all…she is the main carer, she looks after his medication, she sorts out the food, she sorts out the finances, she pretty much does everything…So anyway I've given her the contact details to the Alzheimer's society and then that's it. 'If you want any support, then maybe you can start leaving the leaflets around the house' or things like that. But the real *challenge* here is to get people to come around eventually to having an assessment."

[The GP goes on to describe some of the services available locally. Later he returns to this particular example]

"If they're in either a state of denial or have limited insight, it might be more difficult because you're not really pushing against an open door…It's a difficult one because, I mean, in a way we could always insist that people were seen and say 'Look, you know, I think it's really, really important'. I mean, the sort of, extreme of that would potentially be being a form of bullying because you can, you can literally say 'oh, I really do think you should see them and I don't care what you think, because I think you're dementing and you have to be seen and making the diagnosis is very important for you' which, you know, actually, sounds massively paternalistic and it *is…"*

"I think it is a negotiation as to what one can do. So, you can always negotiate harder and I certainly could have negotiated harder [in this particular case] but I would prefer - I mean, maybe it's a personal style - I certainly would prefer that, you know, they come, or eventually come round to your view. Now, the catch with that is that sometimes what happens is you get a crisis. You could say 'Well, you could have intervened earlier'. Yeah! But that then would have been counter to providing him with any particular form of, you know, autonomy. So, that's a constant struggle, just knowing, 'could I have done that?' …it's a constant struggle. I mean, it's difficult to know, because how would I know anyway whether it was a better or worse decision?"

(Informant 2)

Box 3

GP: “So I thought I must be very, very careful in establishing a diagnostic label. I think I’m…however it’s important to access certain services. If you say you need help for your condition then the help is only available with a certain label, so I cannot say “um, yeh I think she has got some rehabilitation needs and her carer has carer strain”. So I thought if I want to build up a support structure I have to put it under the ‘D’ label, so kind of, the rehabilitation process forces me to attach a label on her forehead. A nasty label. Dementia.”

[the GP goes on to explain how he tentatively proceeded to make some steps towards establishing a diagnosis]

I had some work up to do, to send stupid blood tests for syphilis. I thought ‘Come On, it’s 19th century’ but yes, the memory clinic wants that. X-ray, this and that. I explored what she thinks about the consequences of diagnosis. I think it’s a little bit like counseling for a HIV test. You need to, kind of, be a step ahead before and say “What do you understand dementia is?”

Researcher: “And what did she respond?”

GP: The woman herself didn’t understand. She was like a mute statue next to her daughter who did the negotiation. And I said “It can have very bleak consequences, but not necessarily.” But there was already a run up to it. It didn’t…there were symptoms, there were concerns, the daughter already worked part-time not full-time. So in a way it was also opening doors to an enabling perspective to put something under, to put a jar with a lid, with a big ‘D’ written on it, thinking it helps accessing services. The down side is you are then on the list in our practice. You’re pestered with regular health checks and this and that. You are labeled.

Researcher: Any advice you feel is helpful for other healthcare professionals to keep in mind?

GP: To think about the consequences of diagnosis. Think about what, how it relates to supporting the person and especially thinking about the care structure in place….I’m very, very careful about um, destroying positive outlooks on life with the diagnostic label. Especially if there is not much which can be done….I orchestrated, like a conductor, bringing different concepts in and negotiating, negotiating a future.

(Informant 6)

Research ethics approval

Research ethics approval was granted by Queen Mary, University of London Research Ethics Committee (reference 1071)

Contributorship statement

SD had the idea for the research study. All authors contributed to the design of the study. SD completed all data collection and transcription. All authors contributed to the analysis of the data. All authors contributed to the preparation of the manuscript and its earlier drafts. DS is the guarantor for the paper.

Data Sharing

Anonymised transcripts of interviews are available on request from the corresponding author.

Transparency declaration

DS (guarantor) affirms that the manuscript is an honest, accurate and transparent account of the study being reported and that no important aspects of the study have been omitted.

Acknowledgement

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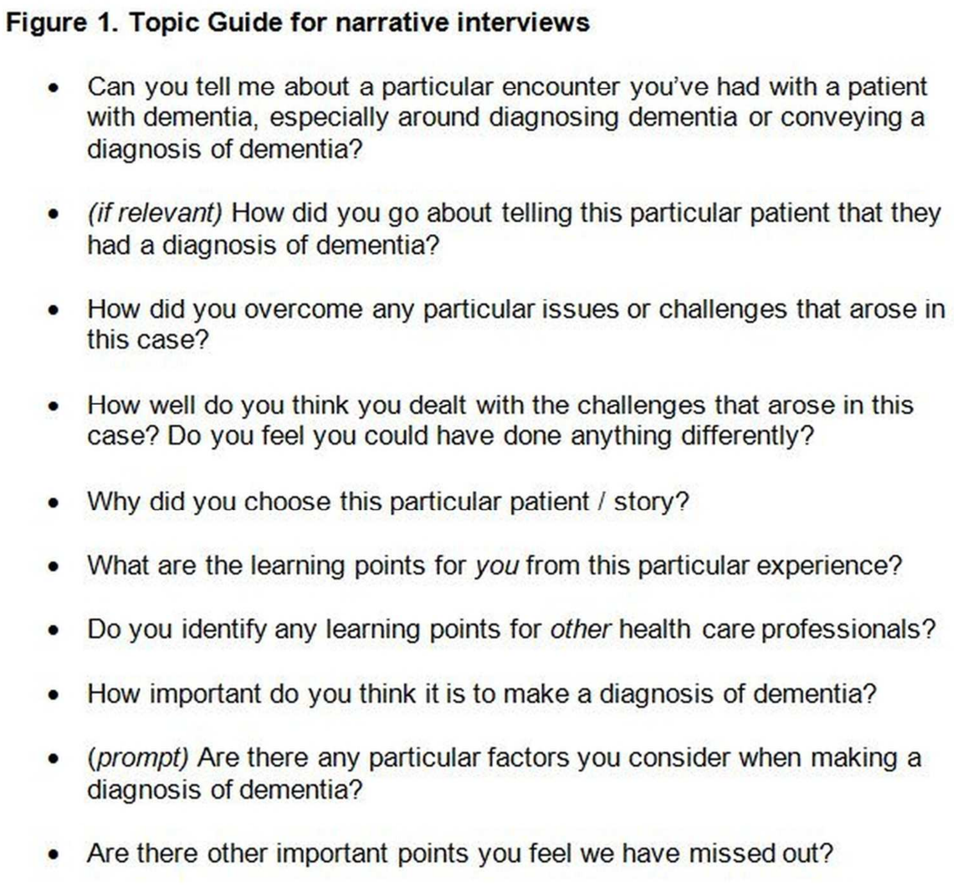

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