Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice

INTRODUCTION

GP's report communicating the diagnosis to be one of the most difficult aspects of dementia management. The value of a timely dementia diagnosis has been argued strongly in recent discussion papers, both in Australia and overseas. Medications may delay or slow the progress of decline if used in the earlier stages of dementia, and a timely diagnosis allows the patient to plan their care and legal arrangements while they are able. Nonetheless, the value of early disclosure of the diagnosis has been debated.

In 2002, Pinner and Bouman reviewed the literature and found reasons for disclosure to patients included: the patient's right to know; managing social needs; enabling the issue of driving to be discussed; getting personal affairs in order; enabling the patient to share anxieties with professional and informal carers; and engagement in activities that may slow down the progression of the disease, including drug therapy. They found reasons for withholding disclosure included: uncertainty of diagnosis; a sense of futility because the patient may no longer have the ability to understand or make use of the information; and a wish to protect the patient from undue distress.

Family/carer(s) may not necessarily want the person they are caring for to be told the diagnosis, or wish to know it themselves. Maguire et al showed 83% of carers said their relative should not be told (although 71% would want to know the diagnosis were they to have dementia). Holroyd et al found only 36% of carers thought it helpful for patients to be told; and Bradford and colleagues' review revealed nine studies where family/carer(s) denied or preferred not to know the patient's condition. However, Pinner and Bouman found that 92% of patients with mild dementia wished to be fully informed of their diagnosis.

Varied reasons are reported for disclosure difficulties. A review of the literature showed one-third of GPs rated explaining the diagnosis of dementia as more time consuming than for other diagnoses. GPs who reported greater difficulty with making the diagnosis and optimal management of dementia were less likely to express attitudes endorsing open communication with the patient and carer, and more likely to have difficulty communicating the diagnosis.

This research examined GPs' perceptions of barriers to disclosing the diagnosis of dementia in the consultation context. It was conducted to explore GPs' perceptions of barriers to disclosing the diagnosis of dementia.

METHOD

Semi-structured, audiorecorded interviews were conducted with GPs from three capital cities and one regional centre in Australia. Interviews were transcribed verbatim and thematic analysis was conducted.

RESULTS

GPs' lack of confidence in having a correct diagnosis, concern to act in patients' best interests, and the stigma associated with the 'dementia' label influenced the disclosure process. GPs found it challenging to identify dementia in the consultation context. It was difficult to raise the issue when both the patient and their family/carer(s) ignore/are unaware of symptoms of cognitive decline. Referral to a specialist was favoured to confirm suspicions, although this did not always result in a definitive diagnosis. Opinions differed as to whether the GP or the specialist was better placed to deliver the diagnosis. GPs preferred disclosure to the patient with their family/carer(s) present; associated issues of confidentiality and the importance of offering hope emerged. The severity of the patient's dementia also guided the diagnostic disclosure process. GPs often used euphemisms for dementia when disclosing the diagnosis, to soften the message.

CONCLUSION

Complex issues surround the disclosure of dementia. Communicating this diagnosis remains particularly challenging for many GPs.
suggests that uncertainty about the diagnosis and what to do contribute to difficulties with disclosure. Disclosure was particularly difficult when made to the patients themselves, rather than their family/carer(s). Allen et al. and Downs et al. found GPs were more likely to inform family/carer(s) of the diagnosis (72% and 99% respectively) than the patient (31% and 55% respectively). GPs also disclosed the diagnosis differently to patients than their family/carer(s) (for example, by using euphemisms). Kissel and Carpenter found wide variation in GPs’ disclosure practices (for example, words used, topics covered), with their strategy differing from patient to patient.

The difficulty with disclosing to patients may be because dementia carries a huge burden of stigma: devaluation, social exclusion, reduced autonomy, and loss of status. Robinson and colleagues showed GPs were cognisant of the emotive dimensions of diagnosis, although they were unsure how to address them. Research indicates that other dilemmas related to disclosure arise for GPs: anxieties about how persons may cope coming to terms with a progressive disability; and ethical issues as medical decisions move from the patient to someone else.

The literature supports these GP concerns for patient wellbeing. While Pinner and Bouman’s clinic sample had no major incidents following disclosure to patients, after 1 year 6% required antidepressant treatment. Holroyd et al found that carers of 28 patients who were told their diagnosis of dementia perceived that 17 took the information well, 19 reacted poorly, and two voiced suicidal thoughts. Only 14 patients appeared to understand the diagnosis. In their review, Draper et al found evidence that people with mild cognitive change and early dementia are at risk of suicidal behaviour.

Many GPs consider dementia diagnosis and care to be in the specialist domain, especially since a longitudinal approach is required for timely, accurate diagnosis. However, specialist referral requires a disclosure that dementia is a possibility, which raises many of the issues above. Moreover, specialist referral may not necessarily result in a definitive diagnosis.

Practical guidance for GPs on how to deliver a diagnosis of dementia appears limited, though a patient-centred approach is considered optimal. More work is needed to understand current GPs’ perceptions and to guide them on issues of disclosure. This study explores Australian GPs’ perceptions of disclosing the diagnosis of dementia.

**METHOD**

This study reports on part of a larger study commenced in 2007, in which GPs participated in a five-site randomised controlled trial of a dementia education intervention in general practice. Three sites were state capital cities of Australia, one a large regional urban centre, and one a smaller regional town. Each site generated a list of possible GP practices within 30 km. Practices were approached in random order and allocated, as they agreed to participate, in a ratio of 2:1, to the ‘intervention’ or ‘waitlist’ group, using an allocation schedule provided independently of the study team, from the Centre for Epidemiology and Biostatistics at the University of Newcastle, New South Wales. The ‘intervention’ group was kept at twice the size of the ‘waitlist’ group to have sufficient power for the main study. Findings from a qualitative study conducted with ‘intervention’ GPs are reported here.

Following their 12-month audits, ‘intervention’ GPs were invited to participate in a semi-structured, audiorecorded interview about their perceptions of the barriers and enablers to the detection and management of dementia in general practice. Between November 2008 and March 2010, 45 GPs (from three capital cities and the similarly urban, large regional centre) consented to do so. All GPs who volunteered were included, regardless of their range of GP experience.

Interviews aimed to elicit GPs’ perspectives on the diagnostic and disclosure process (Box 1). Interviews took place in participating GPs’ practice rooms at GPs’ convenience, before, during, or after their workday. They were conducted by peer educators alongside the educational intervention. The educational intervention...
Box 1. Main interview topics for GPs

- Diagnosing people with dementia
- Factors that make diagnosis of dementia easier
- Who discloses the diagnosis?
- The GPs' role in the disclosure process
- The doctor–patient relationship and the diagnostic and disclosure process
- Barriers to disclosure
- Reactions of patients to the disclosure of a dementia diagnosis
- The role of carer(s) in disclosure of a dementia diagnosis
- What terms are used when communicating a diagnosis of dementia?

Box 2. Educational intervention* for GPs

- Review of baseline data from study site (prevalence of dementia and depression, detection of dementia, confounders and differential diagnosis, referral to support services, review of carer data)
- Making the diagnosis (history of onset and progression of symptoms; assessment of functional abilities; exclude confounders/differential diagnosis; assessment: physical, cognitive, focused neurological examination; pros and cons of disclosure; referral to specialists for confirmation of diagnosis; and access to dementia drugs)
- Managing dementia (monitor patient’s psychiatric status, safety, medication compliance; monitor caregiver distress/depression; refer to support groups; development of an ongoing action plan: health promotion — focus on remaining strengths, diet, and exercise; management of general medical problems, comorbidities, immunisations)

*Note: all educators underwent a training programme on the educational package, either face to face or via teleconference. The educational package, based on Royal Australian College of General Practitioners’ guidelines, was delivered by peer educators via laptop computer and hard-copy support materials.

delivered to all ‘intervention’ GPs involved a PowerPoint® presentation about dementia diagnosis, diagnostic work-up, and management according to strategies incorporated in the Royal Australian College of General Practitioners’ (RACGP) guidelines for the care of patients with early dementia (Box 2). The educator initially discussed prior pooled data from the GP’s study site along with the individual patient data for the participating GP (Box 2). Interviews ranged from 30 to 60 minutes and were informant led as much as possible (Box 1). Although the peer educator acknowledged that it is not always possible to adhere to the RACGP guidelines, the discussion concluded with a representation and reminder of these guidelines concerning dementia (Box 2).

Interviews were transcribed verbatim and numbered (for example, GP1) to preserve anonymity. Thematic analysis involved a constant comparison process, aligning new data with existing codes, and generating new codes, reviewing earlier transcripts for new codes, grouping data into major and subthemes, and identifying negative cases. Following Taylor and Bogdan,26 propositions were created by reviewing and reflecting on the data at the codes and asking questions of the data (for example, what do these quotes have in common? How do the themes relate to each other?). Thus a proposition was a general statement that was grounded in the data,26 which facilitated interpretation of the data. Three experienced qualitative researchers from medicine and psychology backgrounds met and reviewed the coding process and the dominant themes. Agreement or differences in perspectives were discussed, with raw data and the coding process reviewed as needed. Discussions enriched the analysis and overall interpretation of the data.

Interviews were conducted around the same time at three sites, though data collection was delayed in one capital city due to peer educator recruitment issues. Different peer educators and study sites, combined with the pragmatics of treating sites equally, resulted in data collection exceeding analysis requirements. Data saturation was apparent following analysis of 21 interviews. The remaining interviews were reviewed and, while interesting quotes from these added and informed the analysis (for example, quotes from GP22, GP27 appear in the relevant results sections), no new themes were identified.

RESULTS

Analysis revealed that diagnosis of dementia was inherently challenging in the context of GP consultation, although attaining a correct diagnosis was seen as imperative. Three main themes emerged that captured the diagnostic challenges and associated disclosure issues: the GPs’ confidence in having a correct diagnosis of dementia to disclose; acting in patients’ best interests in disclosure of the diagnosis; and dealing with the negative implications of the diagnosis. It is acknowledged that, given the complexity of the data, some overlap and interaction occurred among the themes.

Confidence in having the correct diagnosis to disclose

Prior to disclosure, it was essential to get the diagnosis right, and dementia ‘can be a particularly difficult diagnosis to make’ (GP14). Dementia was considered ‘such a significant diagnosis’ (GP8); compared to ‘disclosing the diagnosis of cancer or any terminal illness’ (GP11) and ‘you want to make sure … your facts are right’ (GP15).

‘You’re not really seeing what’s going on’. The GP consultation was time limited, which was not conducive to identifying dementia:

‘... it’s really difficult to do on someone you’ve never met before in a 15-minute interview... if they’re in the early stages of it,'
you can’t possibly know.’ [GP9]

‘... unless they behave erratically in the room ...’ [GP17].

‘... the thing with all of this [is], unless you look you don’t find — or, you only find when it’s really obvious.’ [GP18].

GPs described using a reactive approach to diagnosis. They relied on patients to alert them to their symptoms, with prompts, such as:

‘“Can you do a memory check ‘cause I think my memory’s not very good”.’ [GP5].

However, this process could be complicated should GPs perceive patients presenting with worries about cognitive decline as often cognitively intact:

‘[Patients who present saying] “I’ve got a problem with my memory” ... Often those people aren’t demented. They’re sort of depressed or nervous or whatever, sleep deprived or unwell physically.’ [GP2]

These other health concerns might be difficult to disentangle from dementia:

‘If there is something like anxiety or depression co-existing ... [it] makes it difficult for us ... you do only see them in that ... brief little time they come in with their ... scripts.’ [GP7].

‘The patients mask it particularly well’. When GPs perceived patients were hiding or denying symptoms of dementia, this made disclosure more difficult:

‘People with early dementia are great at hiding it.’ [GP14];

‘In the beginning they may be in denial.’ [GP4].

However, ‘the hardest thing is if ... the person’s got obvious memory loss and they either, or their family, have chosen to significantly ignore it ... Then trying to bring it up ... it makes it harder,’ [GP8]. Disclosure was ‘easier if the patient is thinking about that diagnosis’, [GP17].

‘Usually the family ... triggers the discussion’. Often the family/carer(s) of the patient raised concerns with the GP:

‘... quite often the partner will notice it long before anyone else does.’ [GP14]

‘It may be their partner or people around them that are saying [something is amiss].’ [GP4].

‘It’s usually the family, or somebody in the family who first triggers the discussion, although sometimes it’s the doctor, sometimes. But that’s unusual.’ [GP13].

Family and/or carer(s)’ involvement in establishing the diagnosis implied their inclusion in disclosure of the findings. Establishing the diagnosis and getting support services in place ‘needs everybody’s cooperation ... they can’t get to the, you know, cognitive clinic themselves, they’ve got to get family to take them.’ [GP23].

‘Specialist colleagues’. GPs favoured referring to specialists for confirmation/definitive diagnosis when dementia was suspected:

‘Sending them to a practitioner in dementia ... the subtext is ... we want to know if you’ve got dementia or not.’ [GP9].

Furthermore, referral was warranted when there were no family/carer(s) available and dementia was suspected:

‘Especially if it’s a person who lives by themselves ... that makes it hard ... so involving ... psychologists that can do the full assessment I think a really good start.’ [GP8]

However, referral to a specialist centre did not automatically result in disclosure of a diagnosis. For instance:

GP26: ‘He went to the memory clinic and they sort of were very unkeen to label him as ... dementia.’

Interviewer: ‘OK, so they didn’t actually tell him?’

GP26: ‘No.’

Acting in the patient’s best interests in disclosure of the diagnosis

‘Giving bad news ... no one likes [to do it].’ Disclosure was deemed essential by some GPs:

‘Patients rights come to the fore ... to know ... as with any condition.’ [GP15].

‘... sometimes I have to make a judgement knowing the patient ... where you’re just far better not to tell them ... as soon as you do ...they go downhill.’ [GP11].
Most GPs considered patients were often ‘fearful of the diagnosis,’ [GP7], ‘they don’t want to be told that. No. Memory problem, no, Alzheimer’s, please don’t tell me that,’ [GP5]. Overall, the disclosure of the diagnosis of dementia was ‘something you do with a bit of trepidation,’ [GP15].

Conflicting views emerged as to whose role it was to disclose to the patient when both the GP and a specialist were involved. A well-developed doctor–patient relationship, like that attained in a continuing-care GP setting, was considered to help the disclosure process:

‘I think it would be a horrible thing to be told by a specialist or a third party that you’ve never met or seen before. It would be far better for that information to have been given to a carer, fine — but, if the information is going to be given to the patient, you’d want it to be someone that knows the patient I think.’ [GP11]

‘I think it is the GP’s role to disclose it. The GP’s known to the patient and generally there should be a trust in the relationship, so it’s an appropriate role for the GP, provided he’s confident and certain of what’s happening.’ [GP15]

Alternately:

‘If someone else could do it [disclose the diagnosis], I, I’d put it back ... put the blame on them you know...I think it makes it a little easier. I can then be supportive rather than sort of knocking the socks off them.’ [GP7]

‘Let a specialist deliver the bad news ... I usually utilise my colleagues as a fall-guy to actually present the diagnosis.’ [GP18]

‘I’m happy and support the disclosure [from the geriatrician] if the diagnosis is definite.’ [GP2]

Possibly, ‘knowing the person makes it easier to diagnose, but harder to disclose ... you know it’s bad news — it’s always hard giving people bad news,’ [GP9]. The desire to avoid delivering ‘the bad news’ seemed associated with concerns over the impact on the doctor–patient relationship. That is, the patient may react negatively and ‘shoot the messenger’ [GP27]. In contrast, some GPs did not perceive disclosure as an issue:

‘I’ve got no, no reservations in telling the patients ... Just being frank with them.’ [GP3]

‘I don’t think disclosure of the diagnosis is a big issue. I’ve never really thought about it, but if I thought someone had dementia ... I’d tell them.’ [GP4]

‘I find it better to do so with other family members there’. When patients were accompanied by family/carer(s), GPs could be judicious with how much information about dementia was disclosed to the patient. Often the family/carer(s) were the focus for information, so that they could understand the condition, which would help them support the patient. Thus the family/carer(s), when available, appeared integral to the disclosure process, especially when the patient may not comprehend or may discount the implications of the diagnosis:

‘I think it’s very important that you spend some time ... with the carers [so] ... the family’s aware of what’s going on ... and they get involved ... If you say it to the patient alone he’s going to go home and say, “Oh he said I’m all right”’. [GP3]

‘I would tell the carer the full story ... more ... than I would [tell] ... the patient, in the vast majority of cases ... [so] someone with some level of control had the information.’ [GP11]

A diagnosis of dementia has ‘implications for the patient and the family’ [GP15] ‘and most ... carers actually really ... want to know what they can do about it’ [GP6]. However, informing about dementia was further complicated by ‘the unpredictability of the decline’ [GP21]. ‘Everyone can fluctuate. One day they’re quite good, another day they’re terrible’ [GP5]. The progress of dementia was individual and varied, not necessarily in accord with lay perceptions of health decline, and challenging for the carer as well as the patient with dementia. Therefore, it was important for the carer to be informed and understand about dementia to help them cope with the consequences of the condition:

‘The best piece of advice ... is to actually explain why they’re doing that and they’re not actually lying, that they don’t have that piece of information, so they’re filling it in with something else. Once the carer understands why they’re saying what they’re saying and doing what they’re doing ... that seems to help the carers more than anything.’ [GP11]

It was also reported that a diagnosis of dementia may ‘be interpreted and used by other family members for their personal gain or for their direction’ [GP22].
Furthermore, family support may not necessarily be forthcoming:

‘I never saw the daughter around at all to give him support. It’s so sad and you see the worse side of people sometimes when you see aged patients.’ [GP12]

‘Confidentiality... [can be] often quite tricky to navigate’. The issue of patient confidentiality emerged in discussion of the disclosure process. The degree of cognitive impairment suffered by the patient and the need to act in the patients’ best interests appeared to guide thinking:

‘One of the difficulties... in the early stages is the issues of communicating back to family and carers about someone who is legally competent... I’ve got to say to the patient... “We should really talk to the family about this and bring them in with you”... And that’s often quite a sticky time.’ [GP14]

‘I’m very conscious about confidentiality, but when I’m dealing with significant cognitive impairment practicality says I need to speak to other, other carers. So in that situation I feel confident about not seeking patient consent.’ [GP21]

‘In the patients in whom dementia is clearly obvious they don’t come in alone, they can’t... So in fact implicit in the visit is the permission to give that diagnosis to whoever is with them.’ [GP22]

Dealing with the negative implications of the diagnosis

‘Offer them some hope’ Disclosure was about maybe confirming people’s fears, then trying to give them a constructive way to move on.’ [GP19]. Sensitive delivery and giving the patient some hope was necessary when delivering ‘bad news’:

‘You give them some lead-in comments... that perhaps they’ve noticed that they’ve been having some difficulties with their memory. So, you’re actually allowing them an opportunity to recognise the problem and discuss it... in a non-threatening way and it also has to offer them some hope... “You have some memory impairment. I mean, but you’re still functioning and living independently and my role is to try and maintain that for as long as possible”... It’s a good opportunity to be able to reassure patients that there’s strategies and things that we can do to maintain their independence... I will often encourage patients to bring in their spouses or their children... it just keeps the lines of communication open...[and reinforces] any decisions that have been made together... I would never support a relative... wanting to hide the information from a patient. I don’t think that’s anybody’s role to do.’ [GP16]

Communicating the diagnosis sensitively reflected the potential impact of the condition on the patients’ quality of life and the underlying stigma attached to the ‘dementia’ label.

‘I don’t disclose it as dementia’ The GPs appeared sensitive to the negative connotations the word ‘dementia’ implied, and tended to couch disclosure in other phrases:

‘I don’t disclose it as dementia, I disclose it more of memory impairment.’ [GP10]

‘I don’t think you necessarily need to use the words dementia or Alzheimer’s disease in front of the patient... Words like “memory loss” or “memory not working as well as it used to” are euphemisms that are quite useful.’ [GP13]

‘Memory impairment or cognitive decline seems to be a bit safer thing... I’ll often use “memory problems” with um family members... I guess getting around the, the word “dementia”... There is some stigma, there’s also... a lot of fear associated with dementia.’ [GP21].

‘A lot of people... use [“dementia” as]... so and so’s really demented... they’re out of their brain and they’re going crazy... it’s got a bad connotation... more stigmatised than anything else... I like to soften it a bit initially by talking about memory loss... that medically we call this dementia but it doesn’t mean you’re crazy or mad.’ [GP20]

Collectively, the above suggests that multiple factors interplay when disclosing the diagnosis of dementia. Cautious disclosure considered the negative connotations associated with dementia. However, use of euphemisms may potentially result in lack of clarity for the patient and family/carer(s).

DISCUSSION

Summary

The context of the GP consultation challenged detection of early dementia, especially if the patient was alone, unfamiliar, or had other health concerns confounding the diagnosis. Often, the
family/carer(s) drew the GP’s attention to the possibility of early dementia. It was particularly difficult for GPs to address the issue when both the patient and their family/carer(s) ignored obvious symptoms of decline. The severity of dementia had implications for the disclosure process.

Referral to specialist colleagues wasfavoured to confirm the diagnosis, and in some instances to convey the diagnosis. It was also considered necessary when the patient lived alone and there was no carer input to verify suspicions. However, even referral to a specialist centre did not always result in a definitive diagnosis. Dementia was a feared condition and opinions differed about the appropriateness of disclosure from a familiar GP or an unfamiliar specialist. Caution in disclosure appeared to be associated with concern about the doctor–patient relationship. GPs were mindful of the negative connotations associated with ‘dementia’. They described using euphemisms in the disclosure process and were mindful of sensitively disclosing the diagnosis and of the need to offer patients a constructive way to move on. Issues of confidentiality also emerged as a medical decision-making shifted from the patient to their family/carer(s). What was common in the disclosure process was the desire to communicate the diagnosis to the patient when they had their family/carer(s) with them.

Strengths and limitations

The interviews were necessarily constrained by the context in which they were conducted. Data collection was limited to ‘intervention’ GPs, as ‘waitlist’ GPs remained the control group for the main study. Different findings may have emerged if the interviews had not been conducted alongside an educational component or if they occurred outside of GPs’ familiar work environments. The study sample was small, and it is possible that the education and interest of the GPs volunteering participation influenced their perceptions. Nonetheless, similar views emerging from different sites suggests the possibility that within Australian culture perceptions exist that may hinder ready disclosure of a diagnosis of dementia. However, it is not appropriate to generalise from such a small qualitative study, and the findings are offered with this caveat in mind.

Comparison with existing literature

This study confirmed that GPs find communicating the diagnosis of dementia difficult.1–5,8,16 The first and second major themes (confidence in having the correct diagnosis to disclose; acting in the patient’s best interests in disclosure of the diagnosis) reflected elements identified by Pinner and Bouman10 (for example, the uncertainty of diagnosis, the patient’s right to know) — elements intrinsic to the disclosure process. GPs’ awareness of the emotive dimensions of diagnosis14,15 emerged in the second and the third major themes (acting in the patient’s best interest in disclosure of the diagnosis; dealing with the negative implications of the diagnosis). In agreement with previous research, GPs interviewed in the present study wished to protect their patients from undue distress,15 disclosed more about dementia to the family/carer(s) than the patient,14,20 and preferred to disclose with other family/carer(s) present.18,19 Sensitively disclosing a dementia diagnosis reflected the well-recognised stigma implicated in delays in dementia diagnosis,24,25,33,30 in accordance with findings of Cody et al17 and Downs et al,21 GPs in this study often couched disclosure using terms other than dementia, and the importance of giving hope in the disclosure process was also raised.21 Sensitively delivering the diagnosis suggests some GPs may use a more patient-centred approach to disclosure, an approach that is gaining attention in the literature.30,33 Similar challenges to confidence in diagnosis and disclosure have been identified in the UK.6,9 The current study extends the existing literature by exploring the disclosure process and the associated impediments as perceived by Australian GPs.

Implications for research and practice

Future research could use these findings to develop survey measures to see if the views expressed in this study exist in the wider GP community. Should this be the case, then a patient-centred communication model to help GPs with sensitive triad consultations could be developed and evaluated in primary care. Having a communication model to complement the best practice guidelines for dementia care may increase GP confidence and improve the detection and management of dementia in primary care.
REFERENCES


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