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Why attend a memory clinic? What do patients and their families want and/or expect?

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ABSTRACT

Objectives: To explore which symptoms led people to seek a memory clinic assessment and what they wanted and expected from that assessment. Did the patient and family want and/or expect diagnostic disclosure and, if so, why? **Methods:** Patients scheduled for memory clinic appointments received two questionnaires by post prior to clinic attendance - one for the patient, one for the next-of- kin – regarding symptomatology, wants, expectations and rationale. **Results:** Ninety-two per cent of patients (N=47) and 88% (N=43) of next-of-kin wanted the patient to be informed of the diagnosis; 84% (N=43) of patients and 86% (N=42) of next-of-kin expected the patient to be informed. Rationales for diagnostic disclosure were categorised under themes of planning, treatment, information, coping strategies and rights. **Conclusions:** Patients and families want diagnostic disclosure in order to plan, receive treatment, receive help and learn strategies to cope. This knowledge is seen as the patient's right.

Key words: dementia, diagnosis, disclosure.

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INTRODUCTION

Disclosure of a dementia diagnosis is not routine. Four General Practitioner studies found that informing patients ranged from 19% - 42% [1-4]. Specialists informed the patient more but also varied, 44% - 100% [5,6,7].

Some doctors were hampered by a lack of diagnostic confidence [1,3,6,8,], dementia severity, patient decision to be informed or not [6,8], potential distress [6,], and negatively affecting hope [6]. Family members were more commonly informed and given more information [8].

Few studies have examined what patients and families want and expect. Four studies that consulted patients with memory problems, found most wanted to be told if diagnosed with dementia [10-14], in the range of 78% [11] to 92% [14], as did three hypothetical studies [15-17].

Research investigating the family/carer perspective reported comparable figures with 75% - 97% wanting the patient informed [10,11,15,16,18,]. However, 93-98% would want to be told if they were the patient [11,14,18].,

Patients, carers and doctors considered diagnostic disclosure important and beneficial. They cited “right to know” [7,18], knowledge assisted information gathering, understanding [12,] and planning [1,7,12,]. It facilitated psychological adjustment and medical care [12,18], provided a name for symptoms [18] and confirmed suspicions [19]. It enabled treatment [1,12,18] and fostered doctor-patient relationships [1]. Awareness assisted patients [16] and could improve quality of life [14].

With the exception of Elson, [12] previous research has consulted patients and/or carers **after** diagnosis. The current study aimed to describe the nature of the memory problem and if, pre-assessment, dementia was suspected as the cause. The study also sought to determine whether patients expected to be told of a dementia diagnosis and why they wanted to know.

METHODS

We employed a mixed methods design, with qualitative and quantitative data collection by questionnaire. Patients received questionnaires with an information sheet by mail preappointment, to prevent response bias. Questionnaires were returned anonymously, reply paid, with return indicating consent.

Study Instruments

Two questionnaires were designed: one for the patient, one for the next-of-kin to complete. Qualitative questions were open-ended. Questions included demographics, a description of the patient's memory problem, whether they were concerned it could be dementia, expectations at the clinic, whether the patient wanted/expected to be informed of the assessment outcome and why/why not, if the next-of-kin wanted the patient informed and why/why not.

The settings were the Memory and Related Disorders Clinic (MRDC), of the Academic Unit for Psychiatry of Old Age, University of Melbourne, St. George's Hospital, Kew, and the Cognitive and Dementia Memory Service (CDAMS) of Melbourne Health, Parkville. Both clinics were funded by Medicare, Australia's national health insurance scheme. The conduct of these clinics was as previously described [13].

Questionnaires were sent consecutively to patients who made an appointment at the MRDC (*n*=76) and at the CDAMS (n=17) until at least 50 had been returned.

The respective Human Research and Ethics Committees (HREC) of both sites approved the study.

Data were analysed using the Predictive Analytic Software Package (PASW), qualitative responses counted by frequency using themes identified by the researchers; quantitative data reported as percentages.

RESULTS

Fifty-three patient and 51 next-of-kin questionnaires were returned able to be analysed.

The MRDC response rate was 70% (patients) and 67% (next-of-kin). Four CDAMS sets were returned (24%) – a lower socio-economic area, with perhaps poorer health literacy.

Demographics

Patients (*n*=53) were 27 male: 26 female; 57% (30) were married, 25% (13) widowed, 13% (7) divorced and 5% (3) single. Next-of-kin (*n*=51) were 16 male: 35 female; 54% (28) were spouses/partners, 24% (13) daughters, 12% (6) sons, 4% (2) friends, 2% (1) sister and 2% (1) granddaughter.

Forty-four patients listed 1-3 memory problems; nine did not answer. Most frequent were word finding difficulties (48%; 21/44) and short term memory (STM) problems (41%; 18/44) (details in *table 1*). Fifty-eight per cent (30/52) were concerned that it could be dementia.

Fifty next-of-kin reported 1-3 memory problems, principally STM problems (50%; 25/50) and word finding difficulties (36%; 18/50) (*see table 1)*. Seventy-one per cent (35/49) were concerned it could be the start of dementia, 25% (12/49) were not, 4% (2/49) were unsure.

Insert Table 1 here

Clinic expectations

Patients were asked about their expectations of the appointment. Sixty per cent (32/53) listed 1-3 responses, 34% (18/53) did not know and 6% (3/53) did not answer. Responses are reported below under emergent themes.

<u>Assessment</u>: 97% (31/32): to be asked questions (*n*=14), have memory tests (*n*=13), a brain scan (*n*=2), discussion of their condition (*n*=1) and an examination (*n*=1).

<u>Information</u>: 22% (7/32).

<u>Help</u>: 34% (11/32): including treatment and support services.

<u>Hope</u>: 6% (2/32) expressed hope that the problem would not be serious.

Next-of-kin were asked about their expectations of the appointment. Forty-four listed 1-3 responses, six did not answer, one reported they would not be attending.

Assessment: All (44/44): memory tests (*n*=25), the patient to be asked questions (*n*=7), brain scan (*n*=4), discussion of the patient's condition (*n*=6), questions about behaviour (*n*=1) or an examination (*n*=1).

Information: 14% (6/44).

Help: 25% (11/44).

Hope: 7% (3/44) were hopeful that *'it's a normal part of ageing'* (*n*=2) or *'fears will be allayed'* (*n*=1).

Expectations of disclosure and rationale

When asked if the assessment outcome were to be a dementia diagnosis, whether the patient expected to be informed, 82% (*n*=42) said 'yes', 4% (*n*=2) said 'no' and 14% (*n*=7) were unsure. Two did not answer. When asked if they wanted to be informed, 92% (*n*=47) said 'yes', 8% (*n*=4) were unsure and two did not answer.

When asked about their rationale, forty-three gave 1-3 reasons; ten did not answer. Emergent themes were: Information, Treatment, Planning, Coping strategies and Rights. *(See table 2).*

Insert table 2 here

Next-of-kin responses were similar. Eighty-six per cent (*n*=42) expected the doctor to tell the patient, 4% (*n*=2) did not and 8% (*n*=4) were unsure. Three did not answer. Eighty-eight per cent (*n*=44) wanted the patient informed, six per cent (*n*=3) did not. Three (6%) were unsure. One respondent did not answer. Ninety-eight per cent (*n*=50) would want to be told if they were the patient.

The rationales for the next-of-kin were similar to the patient. Forty-three next-of-kin offered 1-3 reasons. Eight did not answer. The principal reason was the opportunity to plan. Whether this was for the patient or the next of kin was not specified. See *table 2* for the full list.

One spouse who did not want the patient informed reasoned: *'it would cause more worry and distress'*. A daughter stated: *'not in that setting. Would prefer the family to speak to dad on* *his own territory.'* The spouse who was unsure offered: *'I'm not sure how a definite, expert opinion would affect him. He's a former scientist, wants to be the 'boss', he may become depressed.'* One daughter thought that '*it would be better for the doctor to tell the family and then the family could decide if the patient should be told'*. Another was *'unsure as there is anxiety and resistance.'*

Insert table 2 here

DISCUSSION

The most frequently reported problems were STM loss and word finding difficulties. Patients (58%) and next-of-kin (73%) were concerned that the symptoms could indicate early dementia.

Our study supports the existing literature, most patients with memory impairment pre-diagnosis, post-diagnosis [17,14] or hypothetically [15-17] want to be informed of their diagnosis. Their families support this viewpoint, most of whom want the patient to be told [10,11,15,16,18], in this study, 88%. Despite some family members not wanting the patient informed, 98% would want to know if they were the patient.

However, the number of patients who **expected** to be told was slightly lower than those **wanting** to be told.

Patients and families wanted to be informed in order to plan, receive treatment and learn strategies to cope. They considered it the patient's right to know. The small number of next-of-kin who did not want the patient told, and those who were unsure, were concerned for the patient's well-being. These findings concur with research identifying benefits of disclosing a dementia diagnosis, including the patient's right to know [12,14,17].

Whilst a third of patients reported not knowing what to expect at the appointment, the majority of patients and families expected a routine doctor/patient exchange, memory testing, questions and having brain scans. They were also gathering information to assist with adjustment as most were concerned that the diagnosis would be dementia.

The patients' responses regarding their expectations were realistic; many approaching a specialist appointment for memory impairment being pragmatic about the outcome. Just one hoped that it was a normal part of ageing and one that their fears would be allayed.

LIMITATION

The response rate varied greatly between Kew and Parkville. These two clinics represent different socio-economic areas of Melbourne. Lack of response may have been influenced by apathy, lack of insight or severity of impairment resulting in opting out. A further study surveying a more diverse sample is warranted.

CONCLUSIONS

Patients and families approaching assessment of memory impairment want to be informed of the diagnosis in order to plan, receive treatment, receive help and learn coping strategies.

Conflicts of interest: None.

Key points:

- The principal symptoms that led patients and their next-of-kin to seek assessment of memory impairment were short term memory loss and word finding difficulties.
- Fifty-eight per cent of patients and 71% of their next-of-kin were concerned that it could be the start of dementia.
- The majority of patients and their next-of-kin wanted and expected the patient to be told if the diagnosis was one of dementia.
- Their rationales for diagnostic disclosure were to plan, to receive treatment and information, to learn coping strategies and that this knowledge is the patient's right.

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Table 1:

Question: Can you please briefly describe your/the patient's memory problem?

Patient *n* = 44 (reporting 1 – 3 memory problems) **Carer *n* = 50 (reporting 1 – 3 memory problems)**	**Patient** ***n* (%)***	**Carer** ***n* (%)***
Word finding	21 (48)	18 (36)
Short term memory problem	18 (41)	25 (50)
Loss of previous knowledge/past events	5 (11)	4 (8)
Losing my memory/more forgetful	4 (9)	4 (8)
Geographical difficulties	3 (7)	7 (14)

Sequencing	3 (7)	5 (10)
Intermittent memory problem/memory is selective	2 (5)	1 (2)
Orientation problem	2 (5)	4 (8)
Needing more reminders	2 (5)	
Forgetting what I was going to do	2 (5)	3 (6)
Concentration	2 (5)	1 (2)
Losing track/changing topic mid-sentence	2 (5)	3 (6)
Confusion	1 (2)	5 (10)
Misplacing/losing things	1 (2)	1 (2)
Taking longer to absorb new knowledge	1 (2)	
No major memory problem	1 (2)	1 (2)

* Percentages cannot equal 100 – most patients had >1 symptom

Table 2:

Question: Why do you want to be told of the diagnosis? (patient)

Question: Why do you want the patient to be told of their diagnosis? (next-of-kin viewpoint)

(Italics indicate quotes)

Themes	**Patient responses**	**Next-of-kin responses**
	N=43, 1-3 responses	**N=43, 1-3 responses**
Planning	*To make plans (n=10)*	*To make plans (n=9)*
28% of Patients	*To put my affairs in order (n=1)*	*Where to from here? (n=1)*
28% of next-of-kin	*So that I can arrange my life around it (n=1)*	*To arrange life around it (n=1)*
		To put affairs in order (n=1)
Treatment	*To receive treatment (n=9)*	*To receive treatment (n=6)*
35% of Patients	*To receive help (n=4)*	
14% of next-of-kin	*Improve condition (n=1)*	

	In the hope I can still (sic) the onset of full blown memory loss(n=1)	
Information 40% of patients 23% of next-of-kin	*I want to be aware of what is happening/I want to know what is happening so that I have certainty instead of the reverse. (n=4)*	*Explanation (n=3)*
	Want to know the truth/because(n=3)	*To be aware of what is happening (n=2)*
	Explanation(n=3)	*Understanding (n=2)*
	Where to from here? (n=2)	*Can it be cured? (n=1)*
	Can it be cured? (n=1)	*To be sure of diagnosis (n=1)*
	Can I drive? (n=1)	*All that the doctor wants the patient to know (n=1)*
	I want to know how long it would take (n=1)	
	Can I stay at home? (n=1)	
	Want to know if it can be contained or managed (n=1)	
Make my job easier 19% of next-of-kin		*Assist with acceptance (n=2)*
		Easier to cope if the patient understands (n=2)
		Easier to manage current and future care (n=2)
		Because I think she does not use her brain enough (n=1)
		So she can understand my caring actions (n=1)
Coping strategies	*To learn strategies to cope (n=4)*	*Strategies to improve/retain memory*

26% of patients		*function (n=2)*
9% of next-of-kin		
	Strategies to improve/retain memory function (n=4)	*To learn strategies to cope (n=2)*
	Time to adapt (n=2)	
	To help myself (n=1)	
Concern for well-being of patient		*Allay patient's concerns (n=2)*
14% of next-of-kin		
		Patient would prefer to face problems (n=2)
		Should be told he can no longer drive (n=1)
		Critical to own insight (n=1)
Rights	*It's my life and I should know (n=2)*	*Patient's right to know (n=4)*
9% of patients	*Being left not knowing would be worse (n=2)*	*Should know the truth (n=1)*
16% of next-of-kin		
		Dementia is like any other disease – important that the patient knows the diagnosis (n=1)