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REVIEW ARTICLE

The prevalence and incidence of dementia with Lewy bodies: a systematic review of population and clinical studies

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Background. Dementia with Lewy bodies (DLB) is increasingly recognized as a common cause of dementia in older people. However, its true frequency remains unclear, with previous studies reporting a prevalence range from zero to 22.8% of all dementia cases. This review aimed to establish the population prevalence and incidence for DLB and to compare this to its prevalence in secondary care settings.

Method. A literature review of all relevant population and clinical studies was conducted using PubMed. Additional references from papers found during that process were added to this.

Results. DLB accounted for 4.2% of all diagnosed dementias in the community. In secondary care this increased to 7.5%. The incidence of DLB was 3.8% of new dementia cases. There was a significant increase in DLB diagnoses when using the revised (2005) International Consensus Criteria (ICC) for DLB compared to the original (1996) criteria.

Conclusions. DLB currently accounts for around one in 25 dementia cases diagnosed in the community and one in 13 cases in secondary care. The significantly higher rates of DLB in secondary care may reflect enhanced diagnostic accuracy in specialist settings and/or the increased morbidity and carer burden of the DLB syndrome compared to other dementias. However, the true prevalence is likely to be much higher because DLB diagnoses are often missed, although there is evidence that new criteria aid case identification.

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Key words: Dementia, Lewy body dementia incidence, prevalence, review.

Introduction

Dementia with Lewy bodies (DLB) has been reported as being the second most common dementia subtype in older people following Alzheimer's disease (AD) (Geser *et al.* 2005; Zupancic *et al.* 2011). Nevertheless, DLB remains under-diagnosed, with more than 50% of cases missed (Palmqvist *et al.* 2009). Accurate diagnosis is important for appropriate disease-specific management and for service development; for example, DLB has a different symptom profile and course compared to other dementias, a differential response to cholinesterase inhibitors and a greatly increased susceptibility to severe, adverse reactions to neuroleptic medication (Ballard *et al.* 1998; Wilcock, 2003).

Those with DLB also suffer from higher mortality and use more resources than those with AD of similar severity (Williams *et al.* 2006; Bostrom *et al.* 2007). This is a result of greater functional impairment and increased risk of falls due to a combination of cognitive impairment, extrapyramidal symptoms and autonomic dysfunction (McKeith *et al.* 2006; Hanyu *et al.* 2009; Sonnesyn *et al.* 2009). Caregiver burden and distress are also greater in DLB when compared to AD (Ricci *et al.* 2009). This is probably due to worsening function and the combination of motor and cognitive problems, along with pronounced behavioural disturbances, hallucinations and sleeping difficulties, consequently leading to greater dependence earlier in the course of disease (Ferman *et al.* 2004; Galvin *et al.* 2010). A clearer recognition of the number of patients with DLB is important to inform appropriate resource allocation by health-care bodies and assist with the delivery of local services.

The only previous systematic review of epidemiological studies identified just seven population prevalence and incidence studies and showed a wide variation in the prevalence of DLB of 0–30% of the dementia population (Zaccai *et al.* 2005). However,

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since that review there has been considerably heightened awareness of the clinical syndrome of DLB, with more studies including this as a subtype of dementia to be assessed for, and International Consensus Criteria (ICC) for DLB have been revised in an attempt to improve case detection (McKeith *et al.* 2005). The previous distinction between probable and possible DLB is retained. Probable DLB refers to a clinical syndrome that has been well validated against autopsy and has a high positive predictive value (>75%) (Litvan *et al.* 2003). Possible DLB is a more uncertain category, with the positive predictive value less clearly established but more likely to be ⩽50% (O'Brien *et al.* 2009). The aims of the current study were to (i) provide an updated review including all recently published prevalence and incidence studies; (ii) examine the impact of the introduction of the new DLB diagnostic criteria on prevalence rates; and (iii) compare prevalence estimates from population samples to those from clinical settings. Although the latter are susceptible to referral bias, further knowledge about referral pathways and frequency for those with DLB is important information when planning secondary care services.

Method

A literature search was undertaken in April 2012 using the online medical database PubMed. PubMed was chosen as it provides free access to over 6000 journals containing more than 1 million research papers. Crucially this also includes e-articles prior to print, a function that is not offered by other commonly cited databases such as Scopus or Web of Science (Falagas *et al.* 2007). By sifting through the references of the articles that we read in full, we were confident that we were unlikely to miss studies that may not have been identified in our original search. Papers were limited to English language only with no time restrictions. The following combinations of keywords were used:

(1) 'dementia' AND 'lewy' AND ['incidence' OR 'prevalence'] (543 articles)
(2) 'dementia' AND 'subtypes' AND ['incidence' OR 'prevalence'] (336 articles)
(3) 'dementia' AND 'door-to-door' (75 articles)

From our extensive search of community-based prevalence and incidence studies we found that the term 'door-to-door', used to describe the method of data collection, was common in abstracts and titles and a good way of capturing epidemiological studies. Using this term in a PubMed search uncovered papers not identified by our original search terms.

All titles and abstracts were sieved independently by two authors for suitability for inclusion and a list of papers potentially meeting study inclusion criteria was created. Full papers were then read and those meeting study criteria were selected for inclusion. The bibliographies of selected papers were examined for evidence of references not identified by the aforementioned database search. Those that met the selection criteria were added to the final list. These papers form the basis of this review.

Inclusion criteria

Population-based studies

To warrant inclusion, papers were required to describe an original epidemiological study using a two-step approach to prevalence estimates for DLB or dementia subtypes including DLB. This meant first assessing all members of the population or randomly selected population sample for evidence of cognitive impairment and then following up positive results to classify their impairment into either mild cognitive impairment (MCI) or a dementia subtype. Incidence studies followed up the dementia-free cohort for evidence of emerging disease. A defined 'at risk' population was a requirement, that is over a certain age bracket (usually 65), and the study needed to involve either the total at-risk population or a non-biased, random sample.

Clinical (secondary care) studies

Studies involving consecutive referrals, which included all new cases of dementia and where the explicit aim was to identify the prevalence of dementia subtypes, were included. The use of imaging modalities such as computed tomography (CT), magnetic resonance imaging (MRI) or single-photon emission computed tomography (SPECT) was allowed but did not form part of the inclusion criteria. Retrospective studies were included providing diagnosis was made according to standardized clinical criteria.

Diagnostic criteria

Each included study required the use of a validated diagnostic tool, such as the Mini Mental State Examination (MMSE), in the first phase as part of the screening process to identify potential cognitive impairment. The MMSE is globally probably the most widely used tool for assessing cognition although it should be acknowledged that it is likely to miss early cases of dementia, especially non-amnestic presentations, which are common in DLB (Mitchell, 2009), and the fluctuating course of DLB arguably makes it more likely to be missed than other dementias.

During the second stage, a formal diagnosis of dementia needed to be in accordance with DSM-III-R

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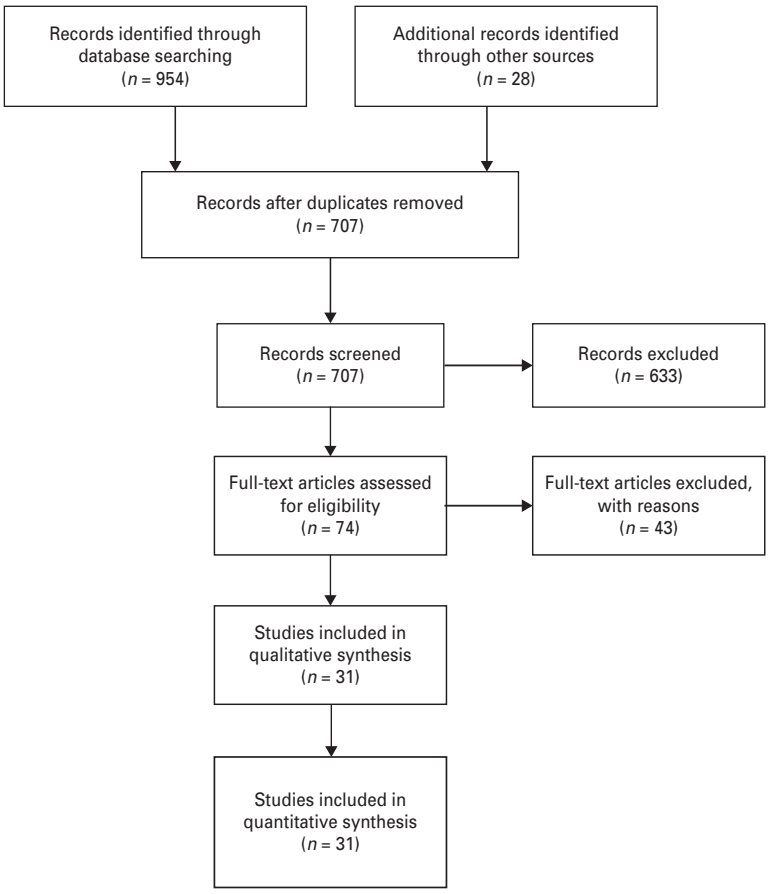

Fig. 1. Systematic review: the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart.

or DSM-IV following a thorough clinical history and examination by at least one recognized medical professional, usually a neurologist, psychiatrist or geriatrician.

To determine the type of dementia on a case-by-case basis, each study was required to have used recognized diagnostic criteria for each subtype and to explicitly mention the use of DLB diagnostic criteria (either the original 1996 ICC or the revised 2005 criteria; McKeith *et al.* 1996, 2005) for diagnosing or ruling out DLB as the final dementia subtype.

Exclusion criteria

Studies based entirely on autopsy collections were excluded.

Statistical analysis

Confidence intervals (CIs) were calculated using the Clopper–Pearson method.

Systematic review

The search for papers was conducted following guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement to ensure quality in systematic reviews (Moher *et al.* 2009). The PRISMA flow diagram summarizes the search (Fig. 1).

Results

Of the 707 abstracts identified by our search, 46 individual papers were selected as a being potentially relevant. A further 28 papers were added following a thorough search of the references from these papers.

A total of 18 population prevalence and three population incidence papers were identified. Of these, seven had been included in the review by Zaccai *et al.* (2005). In addition, 10 clinical prevalence studies were found to meet the inclusion criteria.

The main reason for non-inclusion of studies was the absence of DLB criteria in identifying different dementia subtypes. A significant number of papers using solely autopsy collections were rejected because they used neuropathology as the sole determinant in making a diagnosis, giving rise to the problem of selection bias of autopsy collections. One paper was rejected for

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Table 1. *Diagnostic criteria used in (a) population- and clinic-based prevalence studies and (b) population incidence studies*

(*a*) Population- and clinic-based prevalence studies

2005 revised criteria		Original 1996 criteria	
Population based (2)	Clinic based (2)	Population based (16)	Clinic based (8)
Fernandez Martinez *et al.* 2008	Aarsland *et al.* 2008	Herrera *et al.* 2002	Londos *et al.* 2000
Dimitrov *et al.* 2012	Alladi *et al.* 2011	Stevens *et al.* 2002	Chan *et al.* 2002
		Yamada *et al.* 2002	Harvey *et al.* 2003
		de Silva *et al.* 2003	Takada *et al.* 2003
		Rahkonen *et al.* 2003	Sambrook *et al.* 2004
		Tognoni *et al.* 2005	Yokota *et al.* 2005
		Galasko *et al.* 2007	Shinagawa *et al.* 2007
		Gascon-Bayarri *et al.* 2007	Yoshida *et al.* 2011
		Molero *et al.* 2007	
		Plassman *et al.* 2007	
		Gurvit *et al.* 2008	
		Jhoo *et al.* 2008	
		Arslantas *et al.* 2009	
		Kim *et al.* 2011	
		Yusuf *et al.* 2011	

(*b*) Population incidence studies

2005 revised criteria (2)	Original 1996 criteria (1)
Matsui *et al.* 2009	Miech *et al.* 2002
Perez *et al.* 2010	

failing to use a standardized screening tool for identifying cognitive impairment (Shaji *et al.* 2002).

Diagnostic criteria

Diagnostic criteria used in population- and clinic-based prevalence studies are shown in Table 1, along with diagnostic criteria used in population incidence studies.

Population prevalence

The mean prevalence of DLB in the whole population over 65 was 0.36% or one in 270 people, with a wide range from zero to 21.9% (Table 2). Of those with dementia, 4.2% were found to have DLB. This equates to one in 24 cases. There was a wide variation in prevalence rates across studies. Among the more recent (>2005) studies ,the prevalence of DLB in the over-65 population ranged from zero to 1.2% and from zero to 9.7% of those with dementia. This is a narrower range than the previously reported prevalence of 0–5% of the general population (over 65 years of age) and 0–22.8% of those with dementia (Zaccai *et al.* 2005). Only two studies included possible and also probable DLB cases (Stevens *et al.* 2002; Gascon-Bayarri *et al.* 2007); these reported an increase in DLB diagnoses from 9.7% to 30.5% and from 9.1% to 12.7% of all dementias respectively, once possible cases were added to probable ones.

Population incidence

Annual incidence rates for DLB were found to be 3.8% (range 3.2–4.5%) of new dementia diagnoses and 0.87 (range 0.57–1.4) cases/1000 person-years (Table 3).

Clinical prevalence

The mean prevalence of DLB in clinical (secondary care) populations from the 10 included studies was 7.5%, or one in 13 patients with dementia (Table 4). Prevalence varied from 2.2% to 24.7% of all dementia cases and was overall significantly higher than the proportion of cases identified in population studies (χ^2_1=23.38, p<0.001). This represents a 47–106% (95% CI) increase in the proportion of dementia cases with

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Table 2. *Population-based prevalence studies*

Study	No. in study	Age (years)	No. with dementia	No. of DLB	DLB/over-65 s, % (95% CI)	DLB/all dementia, % (95% CI)
Yamada (2001)	3715	65	142	4	0.11 (0.03–0.28)	0.28 (0.08–0.71)
Ikeda (2001)	1145	> 65	60	1	0.09 (0.00–0.49)	1.67 (0.04–8.94)
Yamada (2002)	157	> 70	19	0	0.00 (0.00–2.32)	0.00 (0.00–17.7)
Stevens (2002)	1085	> 65	72	7	0.65 (0.26–1.32)	9.72 (4.0–19.0)
Herrera (2002)	1656	> 65	118	2	0.12 (0.01–0.44)	1.69 (0.21–5.99)
de Silva (2003)	703	> 65	28	1	0.14 (0.00–0.79)	3.57 (0.09–18.35)
Rahkonen (2003)	601	> 75	137	30	4.99 (3.39–7.05)	21.9 (15.29–29.76)
Tognoni (2005)	1600	> 65	99	3	0.19 (0.04–0.55)	3.03 (0.63–8.60)
Galasko (2007)	1984	> 65	243	1	0.05 (0.00–0.28)	0.41 (0.01–2.27)
Molero (2007)	2438	> 65	196	4	0.16 (0.04–0.42)	2.04 (0.56–5.14)
Fernandez Martinez (2008)	1931	> 65	108	10	0.52 (0.25–0.95)	9.23 (4.53–16.37)
Gascon-Bayarri (2007)[a]	1754	> 65	165	15	0.86 (0.48–1.41)	9.09 (5.18–14.55)
Jhoo (2008)	714	> 65	37	2	0.28 (0.03–1.01)	5.41 (0.66–18.2)
Gurvit (2008)	1019	> 65	93	9	0.88 (0.04–1.67)	9.68 (4.52–17.58)
Arslantas (2009)	3100	> 55	262	0	0.00 (0.00–0.12)	0.00 (0.00–1.4)
Kim (2011)	1673	> 65	351	2	0.12 (0.01–0.43)	0.57 (0.07–2.04)
Yusuf (2011)	322	> 65	9	0	0.00 (0.00–1.14)	0.00 (0.00–33.63)
Dimitrov (2012)[a]	540	> 65	39	2	0.37 (0.05–1.33)	5.13 (0.63–17.32)
Total	26 137		2178	93	0.36 (0.29–0.44)	4.24 (3.44–5.17)

DLB, Dementia with Lewy bodies; CI, confidence interval.
[a] Used the revised 2005 criteria.

Table 3. *Population-based incidence studies*

Study	No. in Study	Age (years)	Dementia incidence (cases/1000 person-years)	DLB incidence in whole population (cases/1000 person-years)	DLB incidence per dementia diagnosis (%)
Miech (2002)	5092	> 65	36.3	0.57	3.2 (6/185)
Matsui (2009)[a]	887	> 65	32.3	1.40	4.4 (12/275)
Perez (2010)[a]	3777	> 65	26.9	1.12	4.5 (28/644)
Total				0.87	3.8 (3.39–4.15)

DLB, Dementia with Lewy bodies.
[a] Used the revised 2005 criteria.

DLB in secondary care compared to the general population.

Probable versus possible DLB

The mean prevalence for all included studies is a reflection of probable DLB cases only. However, four papers also provided prevalence rates for possible DLB (Stevens *et al.* 2002; Yokota *et al.* 2005; Gascon-Bayarri *et al.* 2007; Aarsland *et al.* 2008). Not surprisingly, all reported a substantial increase in cases when possible cases were also included in the DLB subcategory (Fig. 2). Only one of these papers used the revised 2005 criteria (Aarsland *et al.* 2008). It is important for all future studies to provide data separately for possible and probable cases to facilitate cross-study comparison.

Comparing the revised 2005 ICC with the original 1996 criteria

Population prevalence studies that used the 2005 criteria reported a mean prevalence of 8.2% compared to 3.7% among those who used the 1996 criteria, a finding that was statistically significant (χ^2_1=5.96, p=0.01). Clinical prevalence studies using the 2005 diagnostic criteria reported an average prevalence of 11.4% *versus* 6.7% in those who had used the

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Table 4. *Clinic-based prevalence studies*

Study	Prospective (P) Retrospective (R)	No. in study	Age (years), mean (S.D.)	DLB/all dementia (%)
Londos (2000)	R	200	N.A.	24.0 (18.26–30.53)
Chan (2002)	P	102	79 (8.1)	2.94 (0.61–8.36)
Harvey (2003)	P	185	58.7 (1.3)	6.49 (3.40–11.06)
Takada (2003)	R	275	N.A.	2.18 (0.80–4.69)
Sambrook (2004)	P	766	76.8	3.00 (1.91–4.47)
Yokota (2005)	P	464	76.1 (8.4)	3.95 (2.32–6.25)
Shinagawa (2007)	P	483	77.9 (5.6)	10.97 (8.33–14.11)
Aarsland (2008)[a]	P	196	76.1 (7.8)	15.82 (11.01–21.69)
Yoshida (2011)	P	126	75.5 (5.0)	8.73 (4.44–15.08)
Alladi (2011)[a]	P	347	66.3	8.93 (6.15–12.44)
Total		3144		7.47 (6.58–8.45)

DLB, Dementia with Lewy bodies; N.A., not available.
[a] Used the revised 2005 criteria.

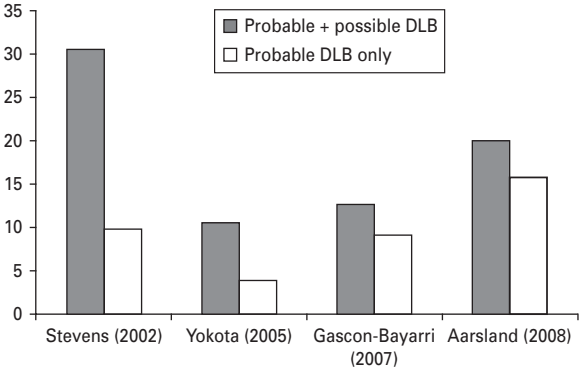

Fig. 2. Probable *versus* probable+possible dementia with Lewy bodies (DLB) in the same study.

1996 criteria. Again this was a significant difference (χ^2_1=14.76, p=0.001).

Consistent with these findings, the only study that directly compared and contrasted the 1996 and 2005 criteria on the same sample found a 25% increase in probable DLB cases identified (Aarsland *et al.* 2008). The two most recent incidence studies both used the 2005 criteria (Matsui *et al.* 2009; Perez *et al.* 2010) and found a 35–40% increase in DLB compared to the only previous incidence study (1996 criteria), although this was not statistically significant (χ^2_1=0.47, p=0.49).

Gender differences

Eight prevalence studies included the gender of those diagnosed with DLB. Of these, five reported disproportionately more females with the disease when controlling for the gender of the sample population (Rahkonen *et al.* 2003; Yokota *et al.* 2005; Gascon-Bayarri *et al.* 2007; Jhoo *et al.* 2008; Yoshida *et al.* 2011) and three reported disproportionately more males (Yamada *et al.* 2001; Aarsland *et al.* 2008; Alladi *et al.* 2011) (Fig. 3). The only incidence study to report on gender found 58.6% of DLB cases to be female but did not report the gender distribution of the original sample (Perez *et al.* 2010).

Age and DLB

Of the 11 population samples that included an average age of participants, there was a positive correlation between age and the proportion of DLB compared to all dementia, although this was not found to be significant (R^2 of 0.25, p=0.45) (Fig. 4). There was no correlation between age and prevalence in clinical studies (R^2=−0.0004, p=0.9) (Fig. 5).

Discussion

The impact of the revised (2005) ICC for diagnosis

Both population-based and clinical studies conducted using the revised 2005 diagnostic criteria for DLB reported significantly higher prevalence rates than those using the original 1996 criteria. This increase in diagnoses was also seen in incidence studies, although this was not statistically significant, most probably because of the much smaller number of incidence studies that have been reported.

There may be alternative explanations for the higher prevalence rates in studies using the revised criteria. DLB has received greater recognition in recent years

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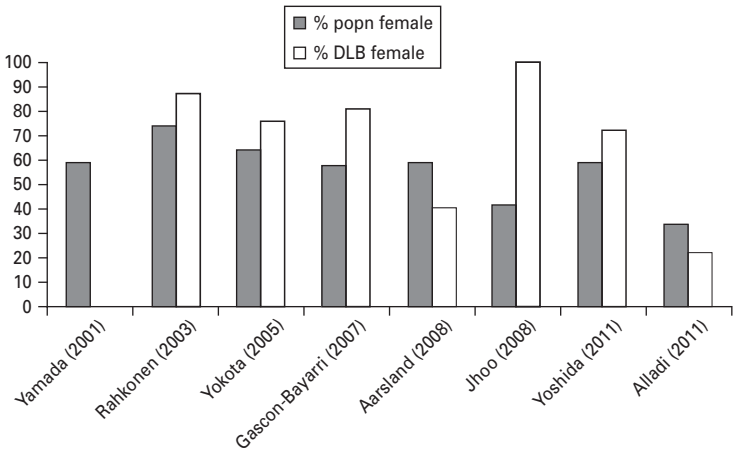

Fig. 3. Gender distribution of dementia with Lewy bodies (DLB). The figure shows the proportion of the population who are female compared to the proportion of DLB cases that are female.

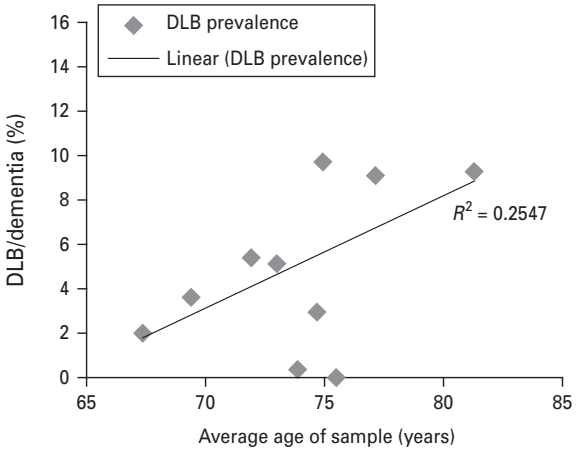

Fig. 4. Population prevalence of dementia with Lewy bodies (DLB) among people with dementia. Relationship to mean sample age (Stevens *et al.* 2002; de Silva *et al.* 2003; Tognoni *et al.* 2005; Galasko *et al.* 2007; Gascon-Bayarri *et al.* 2007; Molero *et al.* 2007; Fernandez Martinez *et al.* 2008; Gurvit *et al.* 2008; Jhoo *et al.* 2008; Yusuf *et al.* 2011; Dimitrov *et al.* 2012).

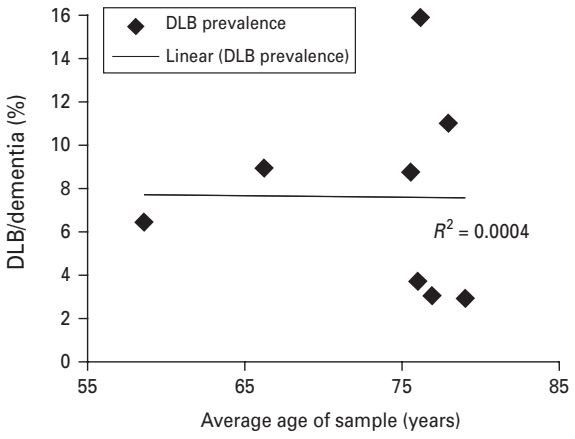

Fig. 5. Clinical prevalence of dementia with Lewy bodies (DLB) among people with dementia. Relationship to mean sample age (Chan *et al.* 2002; Harvey *et al.* 2003; Sambrook *et al.* 2004; Yokota *et al.* 2005; Shinagawa *et al.* 2007; Aarsland *et al.* 2008; Alladi *et al.* 2011; Yoshida *et al.* 2011).

and this increase in awareness arguably makes case identification more likely in the more recent studies, which used the revised criteria. However, we found no evidence to support this explanation as several of those studies continued to use the original criteria yet showed no link between recentness and greater detection rates. It could also be argued that the methodology was better designed to detect DLB in more recent papers using the revised 2005 criteria, although in the absence of universally detailed descriptions of the thoroughness of the diagnostic process, this is difficult to compare. The statistical and empirical evidence that the 2005 guidelines improve detection rates suggests that the revised criteria are indeed more sensitive and that it would be preferable for all future epidemiological studies to use the revised criteria to improve the accuracy of estimates.

Methodological issues: DLB as the focus of the study

The majority of papers aimed to identify dementia prevalence and then categorized this by subtype. Only in four prevalence papers (three clinic-based, one population-based) was the identification of DLB prevalence the primary aim of the study (Londos *et al.* 2000; Chan *et al.* 2002; Rahkonen *et al.* 2003; Aarsland *et al.* 2008). Of these, three provided a detailed description of the neurological examination including explicit mention of extrapyramidal signs (Londos *et al.* 2000; Rahkonen *et al.* 2003; Aarsland *et al.* 2008). Prevalence rates in these three studies

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were high with a narrow range of 19.9–24.9%, suggesting that looking for specific evidence of DLB greatly increases the diagnostic yield. The guidelines for DLB require a thorough examination for extrapyramidal signs and accurate reporting of fluctuations as a minimum. Few papers provided this level of detail in their methods.

Sample age

The mean age of onset of DLB is reported to be 75 years (Barber *et al.* 2001), which may increase the likelihood of underestimating DLB when only younger samples are studied. One large study (n=3100) that did not identify any cases of DLB reported that 50.7% of dementia cases were vascular and 48% AD. These atypical findings may reflect the sample age because 73% were under 70 and over 50% were under 65 (Arslantas *et al.* 2009). Our findings showed a positive correlation between sample age and proportion of the dementia population with DLB. Although this was not found to be statistically significant, it should be further explored. Average age should be a mandatory reporting requirement in future studies and stratifying prevalence by age group would also be useful for more accurately establishing age-related patterns of disease.

Clinic versus population studies

The mean prevalence of DLB in secondary care is 47–105% higher than in the community. This finding may give us some insight into referral patterns. It would seem that individuals with DLB are more likely to be referred to secondary care than those suffering from other dementias. This may be due to the increased burden of symptoms, and greater resource use seen by those with DLB (Ballard *et al.* 1998; Wilcock, 2003). However, this difference may also be explained by the difficulty of accurately differentiating between dementias in large community studies. Detecting clinical differences between AD, DLB and pervasive developmental disorders (PDD) is a challenge for physicians, but clinical differentiation is possible with careful assessment of attention, episodic memory and executive function (Kim *et al.* 2011). This is more realistically achievable in the clinic than in the community (Chan *et al.* 2002). Despite vulnerability to referral bias, the use of clinical studies is therefore still of benefit in estimating population prevalence and should be encouraged. Furthermore, population studies need to be large enough to represent the population but not too large that thorough assessment is not practicable (Barker & Foltynie, 2003). We initially used the Kish population prevalence sample size calculation to suggest a sample size for future studies (Kish, 1965). Assuming a prevalence of 0.36% in the population and a 95% CI, we calculated the necessary sample size to be greater than 4000. This is beyond the scope of most studies and we would therefore favour the more feasible approach of the 10/66 study group, which recommends that dementia prevalence studies involve a sample of between 1000 and 3000 people (Prince *et al.* 2007).

Gender differences

AD is more prevalent in women with dementia than men (67% *v.* 55%) whereas vascular dementia and mixed dementias are more common in men (31% *v.* 25%) (Knapp *et al.* 2007). Parkinson's disease dementia is more common in men (Mayeux *et al.* 1992) and, to date, it has generally been accepted that DLB is also more common in males than females (Klatka *et al.* 1996). The reason for these gender differences is still unclear but it is noteworthy that a previously reported male predominance in DLB was not supported by many of the studies reported here. This may reflect a lack of sex difference or the differences between cohort studies, where the male predominance had been identified, and more representative samples. These findings challenge the gender stereotype and should help to increase the likelihood of accurate diagnosis on a case-by-case basis. Future studies should report the gender of those with DLB.

Conclusions

From published studies, we found the prevalence of DLB to be 4.2% of all dementia cases in the community, with significantly higher rates (approximately 50% more) seen in clinical (secondary care) samples, either reflecting the increased morbidity and carer burden on the DLB syndrome compared to other dementias or more accurate diagnosis in secondary care settings. There was evidence that use of the revised DLB diagnostic criteria do indeed identify a greater number of clinical cases, although ultimately external validation of the diagnostic accuracy of cases (e.g. through an independent consensus panel or autopsy evidence) will be needed to confirm this. The sex distribution is uncertain, with several studies challenging the widely held view that DLB is more common in males. We recommend that future studies investigating prevalence and incidence of DLB use the revised ICC for diagnoses, always report on sex distribution, report separate estimates for possible and probable DLB cases and always include standardized measures of psychiatric symptoms, fluctuation and motor symptoms as provided in the 2005 consensus criteria (McKeith *et al.* 2005). Examples of these include the Neuropsychiatric Inventory (Cummings *et al.* 1994),

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the Clinical Assessment of Fluctuation Scale (Walker *et al.* 2000), and the Unified Parkinson's Disease Rating Scale modified for those with dementia (Ballard *et al.* 1997). Future studies also need to strike a balance between sample size and the ability to perform thorough clinical histories and physical examinations on every participant. Until this optimum number has been agreed, it will continue to be useful to support population prevalences with those from clinically referred samples.

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Declaration of Interest

J. O'Brien has acted as a consultant for GE Healthcare and Bayer Healthcare.

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