


Timely diagnosis of dementia? Family carers' experiences in 5 European countries

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Objectives: Timely diagnosis of dementia is recommended in national strategies. To what extent is it occurring across Europe, what factors are associated with it, and what is the impact on carers emotions of quality of diagnostic disclosure?

Methods/design: Survey of family carers recruited through 5 Alzheimer's associations (Czech Republic, Finland, Italy, the Netherlands, and Scotland). One thousand four hundred and nine carers participated, 84% completing online. Fifty-two percent were adult children, and 37% were spouses, with median age 57. Most (83%) were female.

Results: Nearly half (47%) of carers reported that an earlier diagnosis would have been preferable. Delaying factors included reluctance of the person with dementia, lack of awareness of dementia, the response of professionals, and delays within health systems. Recent diagnoses were no more likely to be considered timely, although professional responses appeared to be improving. Delayed diagnoses were more often reported by adult child carers and where the diagnosis was made in the later stages of dementia, or another condition had been previously diagnosed. In all countries except Italy, the diagnosis was shared with the person with dementia in the majority of cases. Timely diagnoses and higher quality diagnostic disclosure are associated with better adjustment and less negative emotional impact on carers in the short and medium term.

Conclusions: Although the study sample were well educated and likely to be in touch with an Alzheimer organisation, many continued to experience the diagnosis of dementia as coming too late, and further work on public awareness, as well as on professional responses, is needed.

KEYWORDS

adjustment, Alzheimer's, dementia, diagnostic disclosure, family carers, timely diagnosis

1 | INTRODUCTION

In an influential 2011 report, Alzheimer's Disease International¹ recommended that "national dementia strategies should promote early diagnosis and intervention". By 2014, Alzheimer Europe² identified that over half (17/30) of the European countries surveyed identified "measures or interventions for the timely detection of dementia" in their national policy documents on dementia. In the same year, Alzheimer Europe launched its "Glasgow declaration", signed by 153 policy makers from 25 European countries, which included affirmation of the right of every person with dementia to a timely diagnosis.

Timely diagnosis has long been proposed to help prevent crises, facilitate adjustment and coping, and provide access to treatments, support³ as well as to research studies and clinical trials. A recent review⁴ highlighted a range of interventions to which timely diagnosis may facilitate access, including pharmacological and nonpharmacological treatments; case management; information provision; discussion of the future, including advanced decision making and planning; and providing support for family carers.

In this context, it appears that "early" and "timely" have often been used interchangeably,³ but with the prospect of biomarkers allowing an early diagnosis to be made prior to any clinical manifestations, the preference for the term "timely diagnosis" has become explicit. Defined⁵ as "access to accurate diagnosis at a time in the disease process when it can be of most benefit to them (*ie, people with dementia and families*)", such an approach is seen as being more person-centred and respectful of the rights of the individual. This understanding of timely diagnosis emerges also in a qualitative study of UK primary care physicians.⁶ The diagnostic process was seen as collaborative between physicians, people with dementia, and families, maintaining a careful balance between the benefits and risks for the individual, emphasising diagnosis at the right time. The balance of benefits and harms may be influenced strongly by the manner in which the diagnosis is made and disclosed, and the support offered after diagnosis, influencing later adjustment.^{1,5} It is suggested that with good support and preparation, the feelings of shock, grief, anger, and loss that people with dementia and families may experience can be balanced by feelings of reassurance and empowerment.¹

Barriers to timely diagnosis identified across Europe² include system-related issues such as lack of specialist diagnostic services or long waiting lists to be seen by such a service, or an absence of clear pathways, before and after diagnosis. A need for more training and expertise in the recognition and management of dementia is also often cited, particularly in relation to primary care. In addition to general practitioners and the public not being sufficiently aware of dementia, the social stigma related to dementia is often seen as a major obstacle.⁷

Awareness and stigma have, to an extent, been addressed by public information campaigns in many countries, and there are examples of approaches aiming to improve timely diagnosis.² The current study focuses on the experiences of family carers in diverse countries across Europe of the diagnosis of dementia. It aims to identify the extent to which carers experience diagnosis as timely, and the factors associated with their perception, including reasons for delays, and whether

Key points

1. Almost half of the carers surveyed considered that the dementia diagnosis would have been more useful if it had been made earlier. There is no indication that the proportion of timely diagnoses is increasing.
2. Adult child carers were more likely to report that the diagnosis was not timely. Delayed diagnoses were more common where the diagnosis was made in the later stages of dementia, or another condition had been previously diagnosed.
3. Refusal by the person with dementia, professional attitudes, lack of awareness, and system delays all contribute to delayed diagnoses. Of these factors, only professional attitudes appear to be improving.
4. Both a perceived delay in diagnosis and lower quality of diagnostic disclosure lead to greater likelihood of carers reporting negative emotions, both immediately after diagnosis and for months and years afterwards.

more recent diagnostic experiences show an improvement from those prior to the emphasis on timely diagnosis in national strategies. It aims to examine carers' experience of the diagnostic process, including disclosure of the diagnosis, and the impact of this experience over time.

2 | MATERIALS AND METHODS

2.1 | Design

Cross-sectional survey of informal carers of people with dementia. The project team included staff from Alzheimer Europe and from the 5 participating national Alzheimer organisations (Czech Republic, Finland, Italy, the Netherlands, and Scotland). The survey topics and questions were drawn up collectively, using as a basis the format of a previous carer survey,⁸ with revisions and additions to address the aims of the current study. The final questionnaire included 2 items screening for eligibility and 56 questions including demographics of the carer and person with dementia, the symptoms that prompted help-seeking, the pathway through the diagnostic process, the experience of the diagnostic process, and emotions experienced immediately after the diagnosis and subsequently (using an adjective checklist). After piloting through a carers' organisation, the questionnaire was translated professionally from English into Dutch, Italian, Finnish, and Czech, and the translations verified by back translation and rechecking against the English version. An online version of the survey in each of the 5 languages was created on the Bristol Online Survey platform, and a paper version also made available.

2.2 | Participants

To be eligible to participate, the respondent had to be currently supporting a family member or friend who had received a diagnosis of dementia, with both the respondent and the person with dementia resident in 1 of the 5 participating countries.

2.3 | Procedure

Ethical approval was given by Bangor University Healthcare Sciences Ethics Committee. The link to the online survey was distributed through the participating national Alzheimer organisations, by e-mail, social media, and newsletters, and the paper version made available on request or mailed out according to local circumstances between January and July 2017. In the Netherlands, it was not necessary to use a paper version. The plan was to achieve a target of 200 completed carer surveys in each of the 5 countries participating, as in the previous survey,⁸ allowing scope for some within country subgroup analyses. In the event, this number was exceeded in each country. Because of the nature of the online distribution, it is not possible to estimate a response rate for the survey.

2.4 | Data analysis

Online and paper responses were entered into a single SPSS database. Comparisons between countries were made using the chi-squared test for categorical variables and the Kruskal-Wallis test for comparison of medians. To correct for multiple comparisons, Bonferroni corrections have been applied on an analysis by analysis basis throughout. Logistic regression analysis was used to identify the independent contribution of relevant variables to the prediction of whether the diagnosis was seen as delayed or not, using a forward conditional entry method until all variables making a significant contribution had been entered. To test whether there had been any changes with more recent diagnoses, the cutoff of 2014 was selected, comparing diagnoses made from 2014 onwards with those made previously. This reflected the median of the distribution of year of diagnosis and also publication of national strategies in several participating countries. Sensitivity analyses tested setting the threshold year at 2013. A number of items asked about the quality of the meeting where the diagnosis was shared (a) with the person with dementia present (13 items) and (b) with the carer (8 items). These items were drawn primarily from a review of best practice regarding dementia diagnosis disclosure.⁹ Each item was rated on a 5-point Likert scale from "strongly disagree" to "strongly agree" (see Table 6). These items were summed to form 2 quality of diagnosis sharing scales, with Cronbach alphas of 0.83 and 0.86 respectively. Higher scores reflected disclosure that was more in accordance with best practice.

3 | RESULTS

3.1 | Demographics

In total, 1409 carers responded to the survey, with 84% completing online (see Table 1). Fifty-three percent were adult children, and 36% were spouses, with only 2% being unrelated to the person with dementia. The median age of carers was 57, and the great majority (83%) were female. The median age of the people with dementia was 77, and 61% were female. There were differences between countries in most of the demographic characteristics. Notably, there were more adult children responding from the Czech Republic and Italy, and less considering themselves the main carer; less

college-educated carers from Italy; people with dementia in the Czech Republic were less likely to be coresident with the carer at the time of diagnosis and less likely to be living alone in Italy. Another diagnosis had been made before the dementia diagnosis in about a quarter of cases (typically depression [28%], anxiety [6%], or mild cognitive impairment [25%]), but this was less common in the Netherlands and Finland. Nearly half the diagnoses (45%) had been made in 2014 or afterwards, but the proportion was less in the Netherlands (36%). The length of time elapsing between the person with dementia or carer noticing problems and a diagnosis being made was reported to be on average just over 2 years, and was significantly less in Italy and the Czech Republic, although Scotland had the highest proportion of diagnoses made in the early stages of dementia.

3.2 | Delayed diagnosis

Less than 1% of carers considered that the diagnosis had been made too soon, but nearly half (47%) of carers reported the diagnosis would have been more useful if it had been earlier (see Table 2). Carers who considered the diagnosis to be delayed reported a longer time period between difficulties being noticed and the diagnosis being made, with a mean difference of 7 to 8 months (no delay: mean 1.85 years, SD 2.14; delay: 2.44 years, SD 2.12; $t = 4.8$, $P < 0.0001$).

Carers reporting delay were asked to identify contributing factors (see Table 3). The most frequent was the person with dementia refusing to be assessed (38%), but negative professional attitudes were also common with 33% indicating that the first professional seen did not consider anything was wrong and 7% being told by the first professional seen that there was no point in seeking a diagnosis. Lack of awareness of dementia was a relatively frequent factor, with 26% of carers reporting that there had been a delay in seeking help because they considered the problems were "just old age" and 15% reporting they were not aware of dementia. Some delays appeared to be related to health care systems, with 12% reporting there was a long delay in being referred to the diagnostic service and 13% stating that the diagnostic assessment process itself took a long time.

Some differences between countries in the perception of delayed diagnosis were noted, with carers in the Netherlands significantly less likely to report the diagnosis being delayed. Carers from the Czech Republic were significantly more likely to feel that nothing could be done, and, together with carers from Italy, to attribute the problems to old age. Carers from Scotland and Italy were more likely to report that the first professional seen did not consider anything was wrong; in Scotland, the first professional seen was usually a general practitioner, but in Italy, a wider range of professionals was the first point of contact. The length of diagnostic assessments was also more likely to be viewed as a delaying factor in these countries. This was much less of an issue for carers from the Czech Republic and the Netherlands.

Where carers considered that the diagnosis had been delayed, they reported that the severity of dementia at the time of diagnosis was greater. Thus, 55% of delayed diagnoses were made in the middle or late stages of dementia, compared with 27.8% where the diagnosis

TABLE 1 Summary of major demographic characteristics of sample

		Scotland	Italy	Netherlands	Finland	Czech Republic	Total	
Number of respondents	(% Online)	227 (93%)	339 (57%)	268 (100%)	363 (98%)	212 (71%)	1409 (84%)	
Carer gender	% Female	88.4%	80.3%	75.8% ^b	86.9%	82.9%	82.8%	$\chi^2 = 20.0$; $P = 0.001$
Carer median age	Years	57 ^b	50 ^b	62 ^b	62 ^b	57 ^b	57	$H = 72.9$; $P < 0.0001$
Carer education ^a	Secondary	62 (27.6%) ¹	223 (66.2%)	57 (21.3%) ¹	168 (46.4%) ²	93 (43.9%) ²	603 (43.0%)	$\chi^2 = 197$; $P < 0.0001$
	College	157 (69.8%) ¹	99 (29.4%)	202 (75.7%) ¹	159 (43.9%) ²	105 (49.5%) ²	722 (51.5%)	
Main carer? ^a	Yes	154 (68.1%) ^b	173 (51.3%)	177 (66.0%) ^b	207 (57.2%)	105 (49.5%)	816 (58.1%)	$\chi^2 = 73.6$; $P < 0.0001$
	Shared equally with other(s)	22 (9.7%) ^b	64 (19.0%)	34 (12.7%)	50 (13.8%)	41 (19.3%)	211 (15.0%)	
Relationship to person with dementia ^a	Spouse	97 (42.7%)	73 (21.6%) ^b	144 (53.7%) ^b	149 (41.2%)	38 (18.0%) ^b	501 (35.6%)	$\chi^2 = 134$; $P < 0.0001$
	Adult child	104 (45.8%)	219 (64.8%) ^b	103 (38.4%) ^b	184 (50.8%)	131 (62.1%) ^b	741 (52.6%)	
Person with dementia gender	% Female	46.9% ^b	73.9% ^b	57.4%	55.6% ^b	68.4%	60.9%	$\chi^2 = 53.1$; $P < 0.0001$
Person with dementia median age	Years	77	82	77	77	82 ^b	77	$H = 16.38$; $P = 0.003$
Living arrangements at time of diagnosis ^a	Coresident with carer	113 (50.0%)	136 (40.2%)	141 (52.8%) ^b	148 (41.0%)	67 (31.9%) ^b	605 (43.2%)	$\chi^2 = 73.2$; $P < 0.0001$
	Living alone	65 (28.8%)	73 (21.6%) ^b	75 (28.1%)	124 (34.3%)	77 (36.7%)	414 (29.5%)	
Year diagnosis made	Pre-2014	113 (49.8%) ^b	198 (58.4%)	172 (64.2%) ^b	175 (48.2%) ^b	118 (55.7%)	776 (55.1%)	$\chi^2 = 20.0$; $P < 0.0001$
	2014 Onwards	114 (50.2%) ^b	141 (41.6%)	96 (35.8%) ^b	188 (51.8%) ^b	94 (44.3%)	633 (44.9%)	
Another condition diagnosed before dementia diagnosis		57 (25.4%)	104 (31.9%)	51 (19.2%) ^b	74 (20.6%) ^b	67 (31.8%)	353 (25.5%)	$\chi^2 = 21.5$; $P < 0.0001$
Length of time between problems being noticed and diagnosis	Mean (SD) years	2.49 (3.01)	1.61 (1.47) ^b	2.57 (2.17)	2.24 (2.05)	1.64 (1.72) ^b	2.13 (2.15)	$F = 10.88$; $P < 0.0001$
Diagnosis made when dementia in middle or late stage		62 (30.7%) ^b	147 (45.5%)	111 (44.4%)	136 (39.3%)	80 (40.0%)	536 (40.6%)	$\chi^2 = 13.2$; $P = 0.01$

^aMajor categories only shown. Superscript numbers indicate groups of countries not significantly different from each other at 5% level.

^bCountries different from at least 2 other countries at 5% level (Bonferroni correction applied).

TABLE 2 Carers' views of whether the diagnosis came at the right time

	Scotland	Italy	Netherlands	Finland	Czech Republic	Total
Too soon	2 (0.9%)	5 (1.5%)	4 (1.5%)	0 (0%)	0 (0%)	11 (0.8%)
Right time	88 (39.1%)	109 (32.8%) ^a	139 (52.3%) ^a	160 (44.7%)	81 (38.6%)	577 (41.5%)
It would have been better if the diagnosis had been made earlier	106 (47.1%)	173 (52.1%)	97 (36.5%) ^a	175 (48.9%)	104 (49.5%)	655 (47.1%)
Unable to say	29 (12.9%)	45 (13.6%)	26 (9.8%)	23 (6.4%)	25 (11.9%)	148 (10.6%)

$\chi^2 = 42.3$; $P < 0.0001$.

^aCountries different from at least 2 other countries at 5% level (Bonferroni correction applied).

was timely ($\chi^2 = 106.8$, $P < 0.0001$). Where the person with dementia was the parent of the carer, the carer was more likely to report a delay in diagnosis (adult child carer 55%; spouse carer 36%; $\chi^2 = 50.2$, $P < 0.0001$).

To evaluate their independent contributions, severity, carer relationship, and time delay factors were entered into a logistic regression analysis, together with key demographic variables and country. The logistic regression model (Table 4) was statistically significant ($\chi^2 (7) = 181.5$, $P < 0.0001$; Nagelkerke $R^2 = 0.187$). Caring for a parent and diagnosis coming at middle or late stages of dementia each approximately doubled the likelihood that diagnosis would be seen

as delayed, and another condition being diagnosed increased the odds of a delay being perceived by half. Delays between noticing difficulties and seeking help and between seeking help and a diagnostic assessment being commenced both contributed to the perception of delay. Increasing age of both carer and person with dementia reduced the odds slightly. Carer and person with dementia gender, carer education, living arrangements at the time of diagnosis, whether the diagnosis was more recent, and country of residence did not make a significant difference to the model.

Carers who considered the diagnosis delayed were more likely to report negative emotions, including sadness and depression, anger,

TABLE 3 Reasons reported by carers as leading to delay

	Scotland (106)	Italy (173)	Netherlands (97)	Finland (175)	Czech Republic (104)	Total (655)	Chi-squared (P ^a)
Person with dementia refused to seek help	32 (30.2%)	52 (30.1%)	43 (44.3%)	81 (46.3%)	40 (38.5%)	248 (37.9%)	14.15 (0.08)
You, the carer, did not want to seek help	3 (2.8%)	5 (2.9%)	2 (2.1%)	3 (1.7%)	0 (0.0%)	13 (2.0%)	3.29 (1.0)
You, the carer, felt nothing could be done	5 (4.7%)	5 (2.9%)	2 (2.1%)	3 (1.7%)	13 (12.5%)*	28 (4.3%)	22.02 (0.001)
Person with dementia felt nothing could be done	1 (0.9%)	5 (2.9%)	5 (5.2%)	4 (2.3%)	8 (7.7%)	23 (3.5%)	9.18 (0.68)
First professional seen did not consider that anything was wrong	40 (37.7%)*	74 (42.8%)*	31 (32.0%)	46 (26.3%)*	25 (24.0%)*	216 (33.0%)	15.95 (0.04)
First professional seen suggested that it would not be worthwhile pursuing a diagnosis	6 (5.7%)	12 (6.9%)	5 (5.2%)	10 (5.7%)	10 (9.6%)	43 (6.6%)	2.28 (1.0)
We were not aware of dementia	8 (7.5%)	29 (16.8%)	11 (11.3%)	29 (16.6%)	20 (19.2%)	97 (14.8%)	7.92 (1.0)
We were concerned about the consequences if dementia was diagnosed	6 (5.7%)	5 (2.9%)	2 (2.1%)	5 (2.9%)	1 (1.0%)	19 (2.9%)	4.50 (1.0)
We thought it was just old age	17 (16.0%)	59 (34.1%)*	17 (17.5%)	37 (21.1%)	41 (39.4%)*	171 (26.1%)	26.80 (0.001)
Referrals to diagnostic services took a long time	17 (16.0%)	13 (7.5%)	12 (12.4%)	27 (15.4%)	12 (11.5%)	81 (12.4%)	6.66 (1.0)
Diagnostic assessment took a long time	22 (20.8%)*	28 (16.2%)*	7 (7.2%)*	22 (12.6%)	4 (3.8%)*	83 (12.7%)	18.12 (0.01)
Other	17 (16.0%)	18 (10.4%)	24 (24.7%)	26 (14.9%)	15 (14.4%)	100 (15.3%)	10.02 (0.48)

^aBonferroni correction applied. *P* values in bold significant at 5% level.

*Significantly different from at least 2 other countries at 5% level.

TABLE 4 Factors associated with diagnosis being seen as delayed—logistic regression model

	β	SE	Wald	Df	Significance	Exp (β)	95% CI for EXP (β)	
Length of time between changes being noticed and help being actively sought by carer or person with dementia	0.109	0.052	4.402	1	0.036	1.116	1.007	1.236
Length of time between carer or person with dementia seeking help and diagnostic assessment being commenced	0.200	0.054	13.677	1	0.000	1.221	1.098	1.357
Relationship with person with dementia: Carer is adult child	0.618	0.179	11.886	1	0.001	1.856	1.306	2.638
Severity of dementia at diagnosis	0.842	0.101	69.716	1	0.000	2.322	1.905	2.829
Another condition was diagnosed before the diagnosis of dementia was made	0.456	0.147	9.619	1	0.002	1.579	1.183	2.106
Carer age	-0.107	0.041	6.782	1	0.009	0.899	0.829	0.974
Person with dementia age	-0.103	0.041	6.298	1	0.012	0.902	0.832	0.978

Variables not included in the final model: country, diagnosis made after 2013, carer gender, person with dementia gender, person with dementia living alone at time of diagnosis, person with dementia living with carer at time of diagnosis, carer has college education, and carer is main carer or shares equally with other(s).

despair, and worries about the future immediately after the diagnosis, with sadness and depression and despair continuing to the present time, on average 4 years later (see Table 5). These carers were also more likely to report relief at the time of diagnosis.

There was no indication of perceived delays in diagnoses being less frequent in more recent diagnoses. For most countries, a higher

proportion of diagnoses made in 2014 and later were seen as delayed than those made earlier; this difference was significant for the Netherlands (pre-2014: 31%; 2014 onwards: 45%; $\chi^2 = 4.79$, $P = 0.029$). Scotland showed the opposite trend, with delayed diagnoses falling from 51% to 42%, but the difference was not significant ($\chi^2 = 1.94$, $P = 0.164$). However, there were, overall, significantly less delays

TABLE 5 The relationship between emotions reported by carers immediately following diagnosis and at present time and (a) whether or not they considered the diagnosis delayed and (b) the quality score for the diagnosis sharing meeting with the carer (8-item scale)

	Immediately after diagnosis		At the present time		Immediately after diagnosis		At the present time	
	Not delayed: Emotion reported N (%)	Delayed: Emotion reported N (%)	Not delayed: Emotion reported N (%)	Delayed: Emotion reported N (%)	Diagnosis sharing quality scale/Emotion not reported Mean (SD)	Diagnosis sharing quality scale/Emotion reported Mean (SD)	Diagnosis sharing quality scale/Emotion not reported Mean (SD)	Diagnosis sharing quality scale/Emotion reported Mean (SD)
Relief	144 (19.1%)	179 (27.3%)	63 (8.4%)	70 (10.7%)	28.2 (6.4)	29.9 (6.5)	28.5 (6.5)	29.8 (6.6)
		χ^2 ; P		χ^2 ; P		t; P		t; P
		13.44; P < 0.0001		2.23; P = 0.135		3.38; P = 0.001		1.83; P = 0.067
Reassurance	70 (9.3%)	70 (10.7%)	94 (12.5%)	83 (12.7%)	28.4 (6.5)	30.5 (6.6)	28.3 (6.4)	31.3 (6.3)
		0.77; P = 0.38		0.13; P = 0.91		3.2; P = 0.001		5.01; P < 0.0001
Acceptance	209 (27.7%)	157 (24.0%)	355 (47.1%)	299 (45.6%)	28.0 (6.6)	30.2 (5.9)	27.6 (6.8)	29.7 (6.0)
		2.56; P = 0.11		0.29; P = 0.59		5.90; P < 0.001		5.01; P < 0.0001
Worried about the future	525 (69.6%)	517 (78.9%)	444 (58.9%)	376 (57.4%)	29.8 (6.4)	28.2 (6.5)	29.0 (6.4)	28.4 (6.5)
		15.75; P < 0.0001		0.316; P = 0.57		3.37; P = 0.001		1.45; P = 0.146
Sadness / depression	258 (34.2%)	285 (43.5%)	225 (29.8%)	262 (40.0%)	29.1 (6.4)	27.9 (6.5)	29.4 (6.2)	27.2 (6.8)
		12.78; P < 0.0001		15.99; P < 0.0001		2.96; P = 0.003		4.99; P < 0.0001
Despair	93 (12.3%)	124 (18.9%)	77 (10.2%)	98 (15.0%)	29.0 (6.4)	26.6 (6.8)	28.9 (6.5)	26.7 (6.4)
		11.71; P = 0.001		7.27; P = 0.007		4.18; P < 0.0001		3.44; P = 0.001
Anger	70 (9.3%)	100 (15.3%)	50 (6.6%)	68 (10.4%)	28.8 (6.5)	27.3 (6.4)	28.8 (6.5)	27.2 (6.8)
		11.83; P = 0.001		0.64; P = 0.011		2.36; P = 0.018		2.14; P = 0.033

P values in bold significant at 5% level after applying Bonferroni correction.

attributed to professional attitudes in diagnoses made in 2014 and later. The proportion of instances where carers reported the first professional seen did not consider anything was wrong fell from 37% to 29% ($\chi^2 = 4.86$, $P = 0.027$), and the proportion where the first professional seen considered it was not worthwhile pursuing a diagnosis decreased from 8.6% to 4.2% ($\chi^2 = 5.12$, $P = 0.024$). The length of time between problems being noticed and a diagnosis being made did not change significantly over time (pre-2014 mean 2.06 years, SD 2.16; 2014 onwards mean 2.20 years, SD 2.14; $t = 1.14$, $P = 0.254$). The results from sensitivity analyses with 2013 as the cutoff year were similar.

3.3 | The experience of diagnostic disclosure

Carer ratings of quality indicators regarding the sharing and communication of the diagnosis (ie, diagnostic disclosure, see Table 6) were generally favourable. Most items on both scales had a median rating of 4 on a 5-point scale. The exceptions related to prediagnostic counselling (person with dementia asked if he/she wanted to know diagnosis before it was made, and who they wanted it to be shared with) where the median was 2, the carer having an opportunity to speak to the health care professional without the person with dementia present (median 2), and a written summary being provided (median 3).

In all countries except Italy, the diagnosis was usually disclosed to the person with dementia by a health care professional. In Italy, 60% of the carers reported that the person with dementia had not been told the diagnosis, compared with 1.1% in Finland and 4.4% in Scotland, 8.2% in the Netherlands, and 23.2% in the Czech Republic. In only a small proportion of cases did this reflect the expressed wish of the person with dementia (6% and 20% of those not informed in Italy and Czech Republic respectively). The reasons for nondisclosure fell into 4 main categories: not wishing to upset the person, the person would not understand or was not aware, the family thought it unnecessary, and the doctor advised against telling the person. Across all countries, the diagnosis was less likely to be disclosed to a person with dementia that was late stage or severe (54%) compared with middle (69%) or early stage (80%), and this contributes to the higher nondisclosure rates in Italy and the Czech Republic, but notably over half of those diagnosed in the early stages of dementia in Italy were not informed.

The relationship between the reported quality of the diagnostic disclosure and the emotions reported by the carers was examined (see Table 5), especially in relation to acceptance, reassurance, and feelings of sadness, depression, and despair. It was evident that a higher quality of diagnosis-sharing is associated with lower sadness and depression, despair, and greater acceptance and reassurance immediately after diagnosis and some time afterwards (average of 4 years). Results are shown for the 8-item scale based on the diagnosis shared with the carer; very similar results are obtained for the scale relating to a meeting with the person with dementia present.

4 | DISCUSSION

The results of this European survey indicate that from the perspective of family carers, the diagnosis of dementia is timely in only about half

TABLE 6 Quality of diagnosis sharing

Quality of Diagnosis Sharing—Person with Dementia Present	Quality of Diagnosis Sharing with Carer
1. The person with dementia was asked if he/she wanted to know the diagnosis before the diagnosis was made	
2. The person with dementia was asked who else should be involved before the diagnosis was made	
3. The doctor sharing the diagnosis explained everything clearly	1. The doctor sharing the diagnosis explained everything clearly
4. The specific diagnosis was stated (not vague terms such as “forgetfulness” or “memory problems”)	2. The specific diagnosis was stated (not vague terms such as “forgetfulness” or “memory problems”)
5. In your opinion, the person with dementia understood the diagnosis	
6. The meeting was too short (reverse scored)	3. The meeting was too short (reverse scored)
7. There was plenty of opportunity to ask questions	4. There was plenty of opportunity to ask questions
8. The doctor established a good relationship with the person with dementia	5. The doctor established a good relationship with you the carer
9. The doctor mainly spoke to yourself (reverse scored)	
10. The doctor gave you an opportunity to speak to him/her without the person with dementia present	
11. The doctor was well prepared for the meeting, and had all the information needed	6. The doctor was well prepared for the meeting, and had all the information needed
12. A clear written summary of the meeting was provided	7. A clear written summary of the meeting was provided
13. Clear arrangements were made for further contact and follow-up	8. Clear arrangements were made for further contact and follow-up
<i>Cronbach alpha 0.83</i>	<i>Cronbach alpha 0.86</i>

Each item scored on a 5-point scale “strongly disagree”/“disagree”/“neither agree nor disagree”/“agree”/“strongly agree”.

of cases. Their perspective appears consistent with their reports of the length of time that elapsed from noticing something was wrong to a diagnosis being made, and with the severity of dementia at the time of diagnosis. Timely diagnoses are no more common among recent diagnoses than in those made previously, despite the recent emphasis in international and national strategies and guidelines. The most common factor contributing to a delayed diagnosis was refusal on the part of the person with dementia to undergo an assessment. Other contributing factors included lack of awareness of dementia and the response of professionals, as well as delays within health systems. Only the response of professionals appeared to be improving, with less carers reporting that the first professional seen had considered nothing was wrong in more recent diagnoses. There is also a need for improved diagnostic accuracy, with another condition being diagnosed before the dementia diagnosis in a quarter of cases, with a third of these other conditions reported as depression, anxiety or stress.

Our results suggest that the manner in which the diagnosis is shared and communicated may have a considerable effect on later adjustment. There was a clear association between quality indicators of the diagnostic-disclosure process and immediate and later adjustment, in relation to acceptance and feelings of sadness and depression. A difference in diagnostic-disclosure practice across countries was evident, with the diagnosis being shared with people with dementia in Italy much less often than in the other participating countries. Across all countries, practice relating to prediagnostic counselling appeared to be less developed than other aspects.

Adult child carers providing support for their parents reported delayed diagnosis more frequently than other carers (mainly spouses). The reasons for this and for delay being associated with younger age of both carer and person with dementia are unclear. Spouse carers are more likely to live with the person with dementia, and may accommodate to the gradual changes over time, accepting them as a “new

normal”, and may not be seeking an early diagnosis. Child carers, with less frequent contact, may find changes more evident, have other care-giving responsibilities, and be more open to outside help. Although the study included relatively few younger people with dementia, delays in diagnosis may be especially salient where the changes experienced cannot be so readily attributed to age. Further exploration of these differences would be useful.

This study reinforces the importance of timely diagnosis and the quality of the diagnostic-disclosure process.^{1,5} Three of the participating countries were identified in the 2014 Alzheimer Europe report² as having included timely diagnosis in their national policies; the 2 countries not so identified (Italy and Czech Republic) do show differences in the pattern of responses to the survey, and, interestingly, report shorter times between problems being noticed and a diagnosis being made, despite relatively high proportions diagnosed in the middle or late stages. This suggests that in these countries, problems have not been identified until becoming relatively advanced. An Italian Dementia National Plan was issued late in 2014, and timely diagnosis features in 3 of its 4 objectives.¹⁰ It also includes mention of the development of guidelines for the communication of the dementia diagnosis. It may be too early for this plan to have had an impact on the results of this survey.

The need for greater awareness of dementia is also evident, although as yet no evidence of the major awareness campaigns changing attitudes was apparent in relation to changing patterns of response over time of items such as “we thought it was just old age” or “we were not aware of dementia”. How best to reduce the tendency of people with dementia to refuse assessment is not clear. This may be related to stigma, or a sense that nothing can be done, or a belief that the problems are not outside normal expectations. More positive images of dementia in the media may well help, but a clearer postdiagnostic offer of support and treatment may also be needed.

It is important to note that the survey presents only 1 perspective on a timely diagnosis. The perspective of people with dementia may well be different, perhaps leading to assessment being refused. What is timely for the carer may not be timely for the person with dementia, and a process of negotiation may often be needed to bring the perspectives together. This study sample are not a representative sample of carers; they are well educated and perhaps more resourceful than average, and likely to be in touch with an Alzheimer's organisation, so less isolated than many, but still experienced the diagnosis of dementia as coming too late. The experience of other carers may well be more negative. The survey methodology is also limited in that it relies on the recall of carers, which can be influenced by later experiences, and there is no possibility for external validation of durations of time, dementia severity etc.

In conclusion, timely diagnosis of dementia in Europe is not yet the norm, but appears to be desirable not only for any opportunity it may provide to access postdiagnostic support and treatment but also for the opportunity for adjustment, and reducing the negative emotional impact on carers. Further work on public awareness, as well as on professional responses, is needed.

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CONFLICT OF INTEREST

None declared.

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