



Services for people with young onset dementia: The 'Angela' project national UK survey of service use and satisfaction

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Abstract

Objectives: Young onset dementia is associated with distinctive support needs but existing research on service provision has been largely small scale and qualitative. Our objective was to explore service use, cost and satisfaction across the UK.

Methods: Information about socio-demographic characteristics, service use and satisfaction were gathered from people with young onset dementia (YOD) and/or a family member/supporter via a national survey.

Results: Two hundred and thirty-three responses were analysed. Diagnosis was most commonly received through a Memory Clinic or Neurology. The type of service delivering diagnosis impacted on post-diagnostic care. Those diagnosed in specialist YOD services were more likely to receive support within the first 6 weeks and receive ongoing care in the service where they were diagnosed. Ongoing care management arrangements varied but generally care was lacking. Around 42% reported no follow-up during 6-weeks after diagnosis; over a third reported seeing no health professional within the previous 3 months; just over a third had a key worker and just under a third had a care plan. Satisfaction and quality of care were highest in specialist services. Almost 60% of family members spent over 5 h per day caring; median costs of health and social care, 3 months, 2018, were £394 (inter-quartile range £389 to 640).

Conclusions: Variation across diagnostic and post-diagnostic care pathways for YOD leads to disparate experiences, with specialist young onset services being associated with better continuity, quality and satisfaction. More specialist services are needed so all with YOD can access age-appropriate care.

KEYWORDS

(3-10), Alzheimer's disease, care pathways, caregivers, early onset dementia, frontotemporal dementia, rare dementias, service costs, services

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1 | INTRODUCTION

Although dementia predominantly affects older people, an estimated 5.5% of those diagnosed have young onset dementia (YOD); where symptoms develop <65 years.¹ UK numbers are estimated as 42,325.² Those living with YOD have distinctive and wide-ranging needs due to age, life stage,³⁻⁶ and the range of rare diagnoses.⁷ Specialised, tailored, well-integrated YOD services, that provide continuity of care, are widely seen as central to addressing these challenges.⁸⁻¹³ Available evidence, however, indicates problematic issues and gaps in provision. Delays to diagnosis and misdiagnosis are common^{8,11} due to the rarity of YOD and the heterogeneity of presenting symptoms, which leads to multiple pathways to diagnosis.^{13,14} In addition, effective post-diagnostic services are lacking.¹⁵ In a recent UK-wide survey of healthcare professionals involved in services for YOD, 54% reported no access to a consultant with a special interest, 28% reported no post-diagnostic support and only 25% reported access to age-specific post-diagnostic support.¹⁶ Consultation with people with YOD and family carers^{17,18} highlights key barriers to post-diagnostic support, including lack of: age-appropriate services information to allow timely access and poor service continuity in the transition from diagnosis to post-diagnostic support.

Existing studies on post-diagnostic YOD services have tended to be small-scale and qualitative, with a lack of information on service costs.^{8,11,12} This paper reports the findings from a large-scale, UK-wide survey of people living with YOD and carers. The aim was to gather baseline information on current YOD service delivery and explore how patterns of care link to quality of care, user satisfaction and costs, in order to inform commissioning and service provision.

2 | METHODS

A cross-sectional UK-wide survey was conducted, gathering data from people with YOD and/or an involved family member or supporter (referred to from hereon as 'family member') on socio-demographic characteristics, service use, satisfaction and positive experiences of support. This article reports the service use, cost and satisfaction data.

2.1 | Measures

The survey (Data S1) was developed by the research team and piloted twice with members of the project patient and public involvement group to ensure wording and questions were suitable. It included four parts. Part 1 comprised open-ended questions on positive experiences of service support (reported elsewhere¹⁹) and a 7-point Likert-scale rating of overall satisfaction with quality of services. Part 2 requested socio-demographic information about the person with YOD (age, gender, diagnosis, when symptoms appeared, date of diagnosis, number of prescription medications, how long the

Key Points

- In the absence of detailed information on service use, costs and satisfaction for people with young onset dementia (YOD), a large national cross-sectional, self-report survey was conducted of people with YOD and/or close supporters, receiving 233 usable responses
- Nearly 60% of family members/supporters provided over 5 h of care a day for the person with YOD, with family members'/supporters' care being valued at over 20 times the cost of support from formal services
- The majority of respondents were mostly or very satisfied with their care from services with higher satisfaction being associated with being managed by a specialist service and knowing who to contact with questions; reporting nobody or a general practitioner alone managed care on a regular basis was associated with lower satisfaction
- Specialist YOD services performed better than other types of service on quality indicators, including provision of support in the immediate period after diagnosis, continuity of services and providing care plans and key workers

person could be alone, household composition, place of residence, educational level, occupation, employment status, income). Part 3 asked similar socio-demographic questions about family members, their time spent caring, extra hours on household tasks since diagnosis, supplementary help from others, and frequency of any respite services. Part 4 asked the type of service in which the person received the diagnosis and had regular follow-up (YOD-specialist service, memory clinic, older people's mental health, neurology, general practitioner), diagnostic tests, frequency of follow-up appointments and support and services accessed in the past 3 months (6 months for hospital admissions). Four quality of care indicators were embedded (seeing the same professional at each appointment, having a care plan, having a key worker, knowing who to contact with questions about treatment and care). Questions mostly employed a yes/no or multiple-choice format.

The opening question of the survey filtered respondents to four different completion pathways (person with YOD alone, with family member or with paid carer or family member alone). Wording was customised accordingly (e.g., referring to 'you' for person with YOD and 'the person with YOD' when a family member was the respondent).

2.2 | Participants

Those with a confirmed YOD diagnosis and family members/supporters were eligible to participate. People with dementia related

to Down's syndrome, HIV, traumatic brain injury, Huntington's disease or alcohol-use were excluded, as these populations usually access different services. Participants were recruited through 14 UK National Health Service sites, purposively selected to include different diagnostic pathways (specialist YOD services, neurology, generic dementia services). A wide range of third-sector organisations also advertised the survey and information was distributed via Join Dementia Research, a UK National Institute of Health Research register of potential participants. Sample size was not pre-defined but we aimed to recruit as many participants as possible.

2.3 | Procedure

Health Research Authority ethical approval was granted (South Central Berkshire Research Ethics Committee, REC ref.: 17/SC/0296) and data were collected between August 2017 and September 2018. The survey was available through the user-friendly, Bristol Online Surveys platform (<https://www.onlinesurveys.ac.uk>). Paper copies could be requested from the researchers. Capacity to consent was assumed for those completing on paper or online. Respondents were invited to contact the researchers for help if necessary, in which case, capacity to consent was assessed, written consent was obtained and survey completion was conducted via Skype, telephone or face-to-face. Following completion, a list of national sources of support was provided to all respondents.

2.4 | Analysis

Responses to individual questions were combined across survey completion pathways. For analyses that compared completion pathways, responses from a person with YOD assisted by a paid carer were combined with responses from the person with YOD alone, since numbers were small and, in both pathways, responses provided the perspective of the person with YOD. For comparative analysis concerning diagnoses, these were grouped into: Alzheimer, Vascular and mixed Vascular/Alzheimer, Rest (Frontotemporal, Posterior Cortical Atrophy, Lewy body, other, unspecified). Background characteristics were analysed descriptively and compared between pathways using appropriate statistical tests.

Provision of tests at diagnosis and referral to post diagnostic services were compared across types of service in which diagnoses were given. Services received in the last three months (including informal care) were analysed descriptively. Exploratory analyses included: continuity between the type of service attended for diagnosis and for follow-up care; associations between diagnosis and frequency of appointments with the service seen the most; associations between the type of service managing follow-up care and participant location (urban vs. rural), frequency of follow-up appointments, time since diagnosis, number of different health professionals seen and activities attended by the person with YOD in the previous three months, quality of care and satisfaction indicators.

Costs of care (British pounds 2018) were calculated over a 3-month period, based on reported service use, in five groups: nurses and allied health professionals, medical, hospital inpatient, social care, family care (Table S3 gives details and unit costs).

Multiple linear regression was performed for three outcome variables: satisfaction with care, total cost of health and social care, informal caring hours. Predictor variables included the characteristics of the person with YOD and the services they received (see Results for full list). Backward elimination was used to derive an initial model. This was then rerun with just the statistically significant predictor variables, to maximise the number of observations used, owing to the presence of scattered missing data.

3 | RESULTS

3.1 | Sample characteristics

There were 233 usable responses.²⁰ Data were obtained about the person with YOD from all responses ($n = 233$) and from 185 family members (when a family member was involved in completion). In over half the responses, a person with YOD was involved in survey completion, alone ($n = 39$, 16.7%), with a paid carer ($n = 9$, 3.9%) or with a family member ($n = 84$, 36.1%). There were 101 (43.3%) family members completing the survey on their own, meaning family members were involved in almost 80% of all responses. There were no statistically significant differences between survey completion pathways on any characteristic related to the person with YOD or family member (data not shown).

Those with YOD were evenly divided between women and men, with a mean age of 62 years. They reported receiving the diagnosis a mean of 3.8 years previously, at the average age of 58 years (range 37–65). Just over half had Alzheimer's disease and the next most common diagnosis ($n = 30$, 12.9%) was a variant of fronto-temporal dementia; the rest reported a variety of diagnoses, with 18 (7.7%) not knowing or not reporting dementia type. They were taking on average over four prescription medications. A small number reported being in paid employment, living alone or in a care home; just over 10% reported having children living in the household. Just over a quarter of those with YOD were not comfortable to remain home alone at all; just under a quarter were comfortable to be alone for 24 h or longer (Table 1).

Most family members were spouses and female, with a mean age of 59 years. They were taking on average one prescription medication. Over one third were in paid employment and more than half reported giving up work to provide care. Those in employment were, on average, younger (58.9 vs. 63.7 years) and there was less time since diagnosis (2.7 vs. 4.5 years; both, independent t test $p < 0.0005$; Table 1).

The annual household income reported for the person with YOD was low, with a third reporting this to be under £12,000 and almost a further third reporting income between £12,001 and £20,000 (data not shown). £18,400 has been calculated as the minimum for an acceptable standard of living.²¹

TABLE 1 Background information about the person with young onset dementia (YOD) and family member/supporter

Characteristics	Person with YOD N = 233		
	N	n	%
Gender	233		
Male		118	50.6
Female		115	49.4
Ethnicity	230		
White		223	97.0
Highest level of education	230		
≤16 years		74	32.2
18 years		23	10.0
Vocational		45	19.6
University degree		87	37.8
Other		1	0.4
In paid employment	233		
Yes		13	5.6
Live alone	233		
Yes		35	15.0
≥1 child in home	230		
Yes		24	10.4
Current living situation	227		
Own home		212	93.4
Care home		15	6.6
Region of England	231		
North West		27	11.7
North East		95	41.1
South East		46	19.9
Midlands, East		27	11.7
South West		14	6.1
London		8	3.5
Out of England		14	6.1
Type of area	228		
Urban		117	51.3
Rural		111	48.7
Dementia type	233		
Alzheimers		128	54.9
Vascular		21	9.0
Mixed Alzheimers, cerebro vascular		12	5.2
Fronto temporal (Language and behavioural variants)		30	12.9
Posterior cortical atrophy		13	5.6

TABLE 1 (Continued)

Characteristics	Person with YOD N = 233		
	N	n	%
Lewy body		6	2.6
Other		5	2.1
Don't know 14/missing 4		18	7.7
Characteristics	Family member/ Supporter		
	N	n	%
Gender	185		
Male		67	36.2
Female		118	63.8
Ethnicity	182		
White		177	97.3
Highest level of education	181		
≤16 years		38	21.0
18 years		23	12.7
Vocational		35	19.3
University degree		84	46.4
Other		1	0.6
In paid employment	185		
Yes		65	35.1
Live with PwYOD	185		
Yes		147	79.5
≥1 child in home	182		
Yes		30	16.5
Given up work to care for PwYOD	185		
Yes		101	54.6
Relationship to person with YOD	185		
Spouse		143	77.3
Partner		11	5.9
Son		1	0.5
Daughter		13	7.0
Parents		3	1.6
Other relative		7	3.8
Friend, neighbour		7	3.8
Time person with YOD could stay home alone ^c	225		
Not at all		61	27.1
Up to one hour		27	12
Up to half a day		58	25.8
Whole day		28	12.4

TABLE 1 (Continued)

Characteristics	Family member/ Supporter		
	N	n	%
1 day and 1 night		13	5.8
More than 1 day and 1 night		38	16.9
Continuous variables	N	Mean (SD)	Median (IQR)
Age at survey (years)	230	62.20 (5.63)	63 (60 to 66)
Age at diagnosis (years)	207	58.15 (5.18)	59 ^a (56 to 62)
Years with dementia at survey	210	3.77 (3.05)	3 ^b (1 to 5)
Number of prescription medications [10 or more set = 10 for mean and SD]	226	4.10 (2.68)	4 (2 to 5)
	N	Mean (SD)	Median (IQR)
Age at survey (years)	184	59.39 (10.62)	62 (55 to 67)
Number of prescription medications	184	1.98 (2.54)	1 (0 to 3)

Abbreviation: IQR, interquartile range.

^aMinimum 37, maximum 65.

^bMinimum 0, maximum 22.

^cResponse from person with YOD where s/he was involved in completion.

3.2 | Diagnostic services

Over a third of respondents received their diagnosis in a memory clinic, around a quarter in Neurology; with under a fifth in older people's mental health services or a specialist YOD service (Table 2). Eighty-six percent of respondents reported that both brain scans and memory tests were used during assessment. Around 40% of respondents reported receiving no follow-up during the 6-weeks after diagnosis. Rates varied significantly between types of service, being lowest (22%) in specialist YOD services and highest (61%) in Neurology (See Table S2, for detail).

3.3 | Management of ongoing care

Care arrangements varied. About one fifth reported their care was managed solely by a specialist YOD service and another fifth solely by a general practitioner (GP). The rest reported a range of single service arrangements or shared care; around 16% reported nobody managed their care. Those in rural areas were more likely to be receiving care from their GP alone (Table 2).

Almost half of those diagnosed in specialist YOD services continued to receive ongoing care from those services, whereas under a quarter who were diagnosed in another type of service received ongoing care from that same type of service. The rest were discharged to GP care (alone or shared), referred to another service,

reported no on-going management or didn't answer the question. Of those who did not know who regularly managed their care, 40% had been diagnosed in a memory clinic and a quarter in neurology. Nearly one third of all respondents reported having no routine follow-up appointments. Frequency for those who did have appointments varied widely. There was no significant difference between service types, urban or rural location, diagnosis or time since diagnosis regarding frequency of follow-up (Table 2).

3.4 | Professionals seen and activities attended

Approximately 39% reported that the person with YOD had seen no health professional in the last three months. The proportion was highest among those whose care was managed by GPs alone and lowest among those whose care was managed in a specialist YOD service. Sixteen different types of health or social care professionals were listed as involved in care, the most common being mental health nurses, social workers and psychiatrists. Of other service contacts in the last 3 months, just over half had attended social activities, around a quarter had a visiting home carer and an eighth had received a home visit from a voluntary agency (Table 3).

3.5 | Family care

Almost 60% of family members reported spending more than 5 h per day supervising/helping the person with YOD and over 40% reported spending an additional 15 h per week or more on household tasks since the diagnosis. Just over one quarter reported that an organisation took care of the person with YOD for some time on a weekly basis but about 70% reported no regular respite. Just under a third reported occasional attendance at a carer support group (Table 3).

Eighty-three (44.9%) reported having relatives or friends helping with care. Total hours of help per day in the last three months from other relatives and friends showed a mean of 6.1, SD 4.08, median 8, range 0–25.5, interquartile range 2.5–8.3. The maximum hours per day of 25.5 were reported for three respondents where one family member provided 1–2 h per day and other relatives/friends provided support 24/7.

3.6 | Costs of care

Costs of care (£, 2018), over 3 months, are summarised in Table 4. The cost of family care dominated but the distribution was highly skewed. Summed costs of all health and social/home care were under £750 on average (median <£400), whereas estimated average costs for the hours families spent in providing care were almost £10,000 (median >£8000). Only just over a quarter (56 of 229) of people with YOD were reported as having home/social care, with a mean cost, where this was provided, of just over £1000 over 3 months. Costs by survey completion pathway are shown in Table S4.

TABLE 2 Type of service that manages care on a regular basis by frequency of appointments, urban and rural location, and service where diagnosed

Service managing care on regular basis																				
Total	Nobody		GP alone		SSYOD alone		OPMH alone		Neurology alone		Memory clinic alone		Family or residential care		Other ^a		GP and any others (shared care)			
	N	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%		
223	100	36	16.1	43	19.3	45	20.2	24	10.8	15	6.7	3	1.3	6	2.7	31	13.9	20	9.0	
220	100																			
112	55.5	19	17.0	16	14.3	21	18.7	13	11.6	8	7.1	3	2.9	3	2.9	14	12.5	5	4.6	
108	45.5	17	15.7	26	24.1	24	22.2	11	10.2	6	5.6	0	0	2	2.0	17	15.7	5	4.6	
Frequency of appointments with service/doctor seen most often ^b																				
No routine appointments	73	32.7	25	69.4	20	46.5	10	22.2	7	29.2	1	6.7	0	0	2	33.3	5	16.1	3	15.0
More than monthly	11	4.9	0	0	1	2.3	4	8.9	0	0	0	0	0	1	16.7	5	16.1	0	0	
1-3 months	52	23.3	1	2.8	8	18.6	16	35.6	8	33.4	1	6.7	1	33.3	3	50.0	7	22.6	7	35.0
4-6 months	51	22.9	6	16.7	4	9.3	11	25.1	8	33.4	7	46.6	1	33.3	0	0	9	29.0	5	25.0
9-12 months	36	16.1	4	11.1	10	23.3	4	8.9	1	4.2	6	40.0	1	33.3	0	0	5	16.1	5	25.0
Total	223	100	36	100	43	100	45	100	24	100	15	100	3	100	6	100	31	100	20	100
Service where received diagnosis																				
SSYOD, n = 36, 18.1%	36	100	4	11.1	6	16.7	17	47.2	2	5.6	1	2.8	0	0	1	2.8	2	5.6	3	8.3
OPMH, n = 34, 17.1%	34	100	6	17.6	5	14.7	5	14.7	8	23.5	1	2.9	0	0	0	0	5	14.7	4	11.8
Neurology clinic, n = 54, 27.1%	54	100	9	16.7	7	13.0	10	18.5	1	1.9	10	18.5	1	1.9	2	3.7	10	18	4	7.4
Memory clinic, n = 75, 37.7%	75	100	15	20.0	17	22.7	10	13.3	10	13.3	2	2.7	2	2.7	3	4.0	11	14.7	5	6.7
Total, n = 199, 100%	199	100	34	17.1	35	17.6	42	21.1	21	10.6	14	7.0	3	1.5	6	3.0	28	14.1	16	8.0

Abbreviations: GP, general practitioner; OPMH, older people's mental health; SSYOD, specialist service for young onset dementia.

^aAdult mental health/other/any combination not involving a GP.

^bThere was no statistically significant difference between the three diagnostic groups with regard to frequency of appointments with service/doctor seen the most (Kruskal-Wallis test: $p = 0.191$).

TABLE 3 Support for person with young onset dementia (YOD) and carer in previous three months

	0		1		2		3		4		5		6		
N	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
Number of health professionals seen in previous 3 months	227	88	38.8	80	35.2	34	15.0	13	5.7	6	2.6	5	2.2	1	0.4
Number of activities attended in previous 3 months ^a	231	105	45.5	72	31.2	39	16.9	13	5.6	2	0.9	0	0	0	0
Visiting home care	More than once a day		Once a day		4–6 times per week		1–3 times per week		Less than once a week		Never				
	229	7	7.0	5	2.1	6	2.6	26	11.2	12	5.2	173	74.2		
Professional and voluntary sector support for person with YOD															
Professional	N	n, Yes	%	Professional	N	n, Yes	%	Professional	N	n, Yes	%	Professional	N	n, Yes	%
Mental health nurse	232	64	27.6	GP	215	19	8.2	Visit from voluntary organisation (e.g., Alzheimer's Society)	230	29	12.4				
Social worker	232	37	15.9	Consultant	215	16	6.9	Neurologist	226	5	2.2				
Psychiatrist	232	35	15.1	Speech/lang. therapist	232	13	5.6	Counsellor	232	3	1.3				
Occupational therapist	232	32	13.8	Support worker/voluntary	222	9	3.9	Practice/District nurse	228	3	1.3				
Admiral nurse	232	29	12.4	Physiotherapist	232	9	3.9	Complementary therapist	232	2	0.9				
Psychologist	232	20	8.6	Dietician	232	9	3.9		230	29	12.4				
Family support for person with YOD															
Time spent/day supervising and/or helping PwYOD	n	%	0 h	%	<1 h	%	1–2 h	%	2–3 h	%	3–5 h	%	≥5 h	%	
	185	100	17	9.2	16	8.6	12	6.5	13	7	21	11.4	106	57.3	
Since PwYOD diagnosed extra time spent/week on additional household tasks	185	100	15	8.1	17	9.2	25	13.5	27	14.6	20	10.8	81	43.8	
Service support for family carers															
How often an organisation takes care of person with YOD so you can take a break	n	%	Once a week or more	%	Once a month or more	%	Less than once a month	%	Never	%					
	185	100	50	27.0	3	1.6	4	2.2	128	69.2					
How often you attend a support group for carers	185	100	5	2.7	27	14.6	21	11.4	132	71.4					

Abbreviation: GP, general practitioner.

^aWalking group 32; singing group 24; dementia café 44; other 53; none 108.

TABLE 4 Summary of costs of care (£ 2018), over three months, by category of service use, and summed

	1. Allied health professionals	2. Medical	3. Main carer + others (Informal care)	4. Home care (social services) ^a	5. Hospital nights, A&E ^b	6. Total 1+2+3+4+5	7. Health & social/home care, (excludes informal) 1+2+4+5
N	231	226	228	229	227	218	227
Missing	2	7	5	4	6	15	11
Mean	32.77	23.89	9727.36	288.55 ^a	414.36	10,644.88	749.57
Median	26.50	0	8372.00	0	313.00	9372.00	394.00
SD	39.46	47.93	9290.54	806.96	324.52	9410.95	890.44
Min	0	0	0	0	313.00	313.00	313.00
Max	203.00	250.00	53,371.50	4186.00	1717.00	55,807.50	5777.50
25%	0	0	0	0	313.00	541.37	338.75
75%	53.50	31.25	16,744.00	598.00	313.00	17,711.50	639.75

^a170 of 229 respondents had no home care. The mean of those who had any home care was £1119.96 over the three months.

^bTwenty-one (9.0%) people with YOD were reported to have had a hospital admission and 39 (16.7%) to have attended A&E in the previous six months, with 12 having multiple visits (total of 60 visits). Short stays of up to 3 weeks in a care home were reported for nine people.

3.7 | Quality and satisfaction with care

Specialist YOD services performed better than other services on all quality indicators. In specialist YOD services, almost all reported seeing the same professional at each appointment whereas this was the case for only just over half of those whose care was managed solely by their GP. Under a third of the overall sample reported having a care plan and the number with a key worker was not much higher (38%), though in specialist YOD services it was 76.3% (Table 5).

Around 60% of respondents reported that their care was mostly or very good whilst 24% felt their care was mostly or very poor, the rest being equivocal. The mean scores suggest people receiving care from specialist YOD services were most satisfied. Family members completing the survey alone expressed lower service satisfaction than was expressed through other completion pathways (Table 5).

3.8 | Regression modelling

Five variables explained 30.2% of the variation in satisfaction scores. Knowing who to contact, being managed in a specialist YOD service and living in the south-east of England were positively associated with satisfaction; reporting nobody or a GP alone managing care on a regular basis were associated with lower satisfaction (Table 6).

Total costs of health and social care over three months were associated with the amount of time the person with YOD could comfortably be left alone (higher cost with less time person could be left alone), dementia diagnosis (Alzheimer's less cost than any other type) and region (higher cost in South-East England) but this model explained only 12% of variation in costs (Table 6).

Hours of care provided by family per day were predicted by the amount of time the person with YOD could comfortably be left alone (more caring hours when person could be left alone for less time), the service managing care (more caring hours when shared care with GP) and region (more caring hours when in north-east England), but only 19% variance in caring hours was explained by this model (Table 6).

4 | DISCUSSION

This UK survey has established information about services used by people living with YOD in England. The findings highlight the variation in routes to assessment and diagnosis and in ongoing care management arrangements. Although diagnosis in neurology or mental health services facilitates exclusion of other mental or physical health conditions, a disadvantage was the lack of continuity in the care pathway to ongoing care management. The proportion of respondents receiving ongoing management through the service that had provided diagnosis was under a quarter in all settings, except specialist YOD services where it approached half. Also, the majority of those who did not know who regularly managed their care had been diagnosed in memory clinics or neurology.

As identified in other research,¹¹ the data confirm distinctive needs associated with YOD in relation to family issues (10% had children at home); employment-related issues (5.6% were still working) and financial impact (over half of family members had given up work to care and a high proportion reported relatively low household income).

Consistent with the findings of Mayrhofer et al.'s review,¹¹ however, there was considerable variation in who respondents

TABLE 5 Quality of care indicators by service managing care on a regular basis

Quality of care indicators. Do you	Who manages care on a regular basis																													
	GP alone N = 43			SSYOD alone N = 45			OPMH alone N = 24			Neurology alone N = 15			Memory Clinic alone N = 3			Family, Residential N = 6			Other ^a N = 31			GP shared with other N = 20			Total N = 233					
	n	%	n	n	%	n	n	%	n	n	%	n	n	%	n	n	%	n	n	%	n	n	%	n	n	%	n	n	%	
...see same professional each time?	15	41.7	23	53.5	44	97.8	17	70.8	12	80.0	3	10.0	4	66.7	25	80.6	14	70.0	157	70.4										
...have a care plan?	2	5.7	13	37.1	16	47.1	6	30.0	2	14.3	0	0	0	0	9	40.9	7	41.2	55	30.2										
...have a key worker?	5	13.9	6	16.7	29	76.3	9	40.9	2	13.3	1	33.3	1	25.0	14	48.3	9	52.9	76	38.0										
...know who to contact with questions about treatment or care?	16	44.4	27	64.3	38	86.4	17	70.8	10	66.7	1	33.3	5	100	22	71.0	14	73.7	150	68.5										
Satisfaction score, scale 1–7, where 1 is highest satisfaction and 7 is lowest	1	2	3	4	5	6	7	1	2	3	4	5	6	7	1	2	3	4	5	6	7	1	2	3	4	5	6	7		
	50	21.5	49	21.0	21.0	3	1.3	36	15.5	1	0.4	39	16.7	13	5.6	26	11.2	16	6.9	233	100									
	99	42.5%	40	17.2%	40	17.2%	40	17.2%	39	16.7	13	5.6	42	18.1%	42	18.1%														
Satisfaction score by service that manages care on a regular basis ^b	Nobody N = 36	GP alone N = 43	SSYOD alone N = 45	OPMH alone N = 24	Neurology alone N = 15	Memory clinic alone N = 3	Family, Residential N = 6	Other ^a N = 31	GP shared with other N = 20	Total N = 233																				
Mean, standard deviation	4.7 1.9	3.7 4.0	2.2 4.0	3.1 3.0	3.1 2.0	3.3 4.0	3.3 3.0	2.9 2.0	2.0 2.4	3.2 3.0																				
Median, interquartile range	5 3-6	4 4	2 2-6	2 1-4	2 2-4	4 2--4	3 2-5	3 1-5	2 1-4	3 2-4																				
Satisfaction scores by respondent group ^c	Person with YOD (alone or with paid carer)										Person with YOD with family member/supporter										Family member/supporter alone									
Mean, standard deviation	2.87	1.84	2.79	1.81	3.76	1.82																								
Median, interquartile range	4	2-5	2	1-4	2.25	1-4																								

Abbreviations: GP, general practitioner; OPMH, older people's mental health; SSYOD, specialist service for young onset dementia.

^aAdult mental health/Other/any combination not involving a GP.

^bKruskal Wallis test <0.0005.

^cKruskal Wallis test <0.0005.

TABLE 6 Results of regression modelling (final models)

(i) Satisfaction with care		Middle of satisfaction scale	
4.183	Constant		
-1.450	Know who to contact	$p < 0.0005$	1 = yes, 2 = no; satisfaction higher if know who to contact
+1.216	Nobody manages care	$p < 0.0005$	Satisfaction worse if no one manages care
+0.606	GP manages care alone	$p = 0.039$	Satisfaction worse if GP manages care
-0.688	SSYOD manages care alone	$p = 0.020$	Satisfaction higher if SSYOD manages care
-0.556	Region south East	$p = 0.042$	Satisfaction higher if person with YOD lives in the SE
$N = 217$; $R^2 = 0.309$			
(ii) Total cost of health and social care (AHP + Medical + Home/social care + Hospital), over three months			
1498.08	Constant		
-149.52	How long comfortable PwYOD being home alone	$p < 0.0005$	1 = comfortable alone not at all to 6 = comfortable alone more than 1 day and 1 night. (£149.52 per point on the scale; point 1 is £149.52 × 5 = £747.60 more costly than point 6)
-259.13	Alzheimer's only	$p = 0.051$	Someone with Alzheimer's only cost £259.13 less than any other diagnoses
-403.53	Living in the SE	$p = 0.011$	Someone living in the SE are costs are 403.53 less than anywhere else in the country
$N = 223$; $R^2 = 0.119$ (poor)			
(iii) Informal caring hours per day			
7.841	Constant		Estimated number of hours informal care per day
-0.896	How long comfortable PwYOD being home alone	$p < 0.0005$	1 = not at all to 6 more than 1 day and 1 night; each point on the scale adds 0.9 h to caring per day.
+2.258	Care managed by shared care with GP	$p = 0.025$	If care managed by shared care, 2.336 more hours of informal care per day
+1.202	Living in the NE	$p = 0.046$	Higher caring hours if live in North-East England
$N = 167$; $R^2 = 0.185$ (fair)			

Notes: Predictor variables: age; gender; highest education level; whether in paid employment (yes/no); whether live alone (yes/no); urban versus rural location; number of years with dementia; number of prescription medications; diagnosis of Alzheimer's alone (yes/no), diagnosis of vascular or mixed (yes/no), with not having Alzheimer's or vascular/mixed as the control/comparator; how comfortable being home alone (scale of 1-6); service that manages regular dementia care (nobody/GP alone/specialist YOD service alone/older people mental health/neurology/shared care with general practitioner/with 'other being the control/comparator); region of England of residence; whether has key worker (yes/no); whether has care plan (yes/no); whether has a tracker (yes/no); whether know who to contact for advice (yes/no); whether see same professional each time (yes/no).

Abbreviations: AHP, allied health practitioner; GP, general practitioner; SSYOD, specialist service for young onset dementia.

(i): Satisfaction scored: 1 = very good all respects to 7 = very poor in all respects. Best situation would be: 4.183 -1.450 (if know who to contact) -0.688 (if managed by SSYOD) -0.556 (if live in SE) = 1.489 (i.e., satisfaction is between 'very good in some respects' and 'very good in all respects'). Worst situation would be: 4.183 -0 (if know who to contact) +1.216 (if managed by Nobody) -0 (if do not live in SE) = 5.399 (i.e., satisfaction is between 'mostly poor' and 'very poor in some respects').

(ii): Best situation (least cost) would be: £1498.08-£897.12 (£149.52 × 6 = £897.12 for point 6 on comfort at home alone scale)-£259.13 for Alzheimer's diagnosis-£403.53 because live in SE = -£61.70. But the five people with that combination (score 6, have Alzheimer's, live in SE) had total costs ranging between £400 and £600. Worst situation (most cost) would be: £1498.09-£149.52 (point 1 on comfort at home alone scale) = £1348.56. The maximum cost over three months recorded by participants was over £4000 over three months (i.e., the model predicts poorly).

(iii): Best situation (lowest caring hours) would be: if comfort with leaving person with YOD home alone score = 6 and not shared care: 7.841 - 5.376 (0.896 × 6) = 2.47 h (but some respondents reported zero caring hours). Worst case (highest caring hours): if comfort with leaving person with YOD home alone score = 1 and shared care and live in NE: 7.841 - 0.896 + 2.358 + 1.202 = 10.41 h (but some people report up to 25.5 h per day caring).

reported as co-ordinating their ongoing care, with only about one in five managed by specialist services. Overall, the lack of support was striking: 42% reported no follow-up within 6 weeks of diagnosis; 16% reported that no service managed their ongoing care; during the previous three months, almost half had attended no social activities for people with dementia, over 80% had no contact with a dementia-related charitable body (e.g., Alzheimer's Society) and around 70% of family members had neither attended a carers' group nor had any organisation to provide care to give them a break. While it is possible that many people with YOD, and supporting family members, chose to manage without support, it also seems possible that appropriate services were not available¹⁷ or there was no sign-posting information.²²

The survey confirmed suggestions from previous work⁸⁻¹³ that care is superior in specialist YOD services. Those diagnosed in specialist services were far more likely to receive a follow-up appointment within 6 weeks of diagnosis and more likely to have ongoing care management appointments at least quarterly. People diagnosed in YOD services were more likely to receive ongoing care management from the same service and were more likely to see the same professional at each appointment. More of those attending specialist YOD services reported having a care plan. Satisfaction scores were higher when care was provided through a specialist YOD service or a shared care arrangement. These findings were confirmed by regression modelling in which being in receipt of specialist YOD services made a positive contribution to service satisfaction. Whilst overall satisfaction varied, and low services use was reported,⁸ many people were satisfied with their care and offered examples of good quality support (reported elsewhere¹⁹).

The survey showed the significant contribution to caring by family members which dominated the costs of care. Median formal health and social care costs for those with YOD were under £400 compared to the estimated £8000 costs per family per 3 months. Costs of care of older people with dementia also show that unpaid care dominates.²³ Average formal health and social care costs for older people with moderate dementia in the community in their second year post-diagnosis have been estimated as £2988 (£:2015) and family costs as £5184 (£:2015).²³ It is notable that our survey found lower service costs and higher family costs for YOD than calculated for older people with dementia. Regression modelling confirmed that costs were positively related to the level of independence of the person with dementia, proxied by the amount of time they could be left alone, as also found for all-age dementia care.²³

One unexpected finding was that those with YOD were being prescribed significantly more medications than family members/supporters, even though they were similar in many aspects of social demography. Even though their medications may have included an anti-dementia medication, this difference raises an issue about the health and medication use of those with YOD which may be worthy of further exploration, particularly given previous research indicates high levels of psychotropic drug prescription for people with YOD living in the community.²⁴ The significant contribution of region, to respondents' satisfaction with services, service costs and amount of

family care, implies possible geographical variation in provision.¹⁶ This could imply the need to level up services across the UK or could be due to regional cultural differences.

4.1 | Strengths and limitations

The survey achieved a large sample with over half of responses directly involving people living with YOD. A reasonable representation across UK regions, types of dementia, age of onset, current life situation and degree of independence/dependence was achieved. Although mean time since diagnosis (3.8 years) was relatively short, there was a relatively even split of those providing care for under, and over, 5 h per day (42.7% vs. 57.3%), and in the extent to which people with YOD could be at home alone, implying a reasonable degree of variation in extent of impairment due to dementia.

While this was the largest UK study focused on services for YOD to date, the numbers of those with rarer dementias were small, leading to a decision to combine a range of different diagnoses into an 'other' category for comparative analyses. Consequently, we were unable to discern different patterns between diagnostic groups. Furthermore, people with more severe cognitive impairment may have been under-represented. These areas deserve further investigation, in particular to consider the service profile and satisfaction of those with fronto-temporal dementia (FTD), given the distinctive impact of FTD diagnoses. In addition, the survey relied on self-report from those with dementia or their supporters so information may include errors. Compromises in the survey questions were made to achieve a balance between accessibility and comprehensiveness, which means some detail could not be precisely gathered.

4.2 | Clinical implications

The findings demonstrate that specialist YOD services provide higher quality care both by objective indicators and in satisfaction ratings by people with YOD and family members. This, in the context of wider evidence that interventions and activities provided in generic dementia services are inappropriate and unacceptable for those with YOD,^{15,17,18} implies that local commissioners should seek to configure dementia services to include specialist YOD teams. Where diagnosis does not take place in a specialist YOD service, attention needs to be paid to transitional arrangements between diagnosis and post-diagnostic support.

5 | CONCLUSIONS

There is great variation within diagnostic care pathways and ongoing care management for YOD in the UK, leading to disparate experiences. Overall, our survey respondents received few services and absorbed few resources. Specialist YOD services were associated

with better continuity, quality and satisfaction and appeared to be in the best position to meet care needs. However, respondents in receipt of specialist care were in the minority, indicating that further specialist services should be commissioned. Family members are providing significant amounts of care on a daily basis with little formal support, and meeting their needs is also a priority.

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CONFLICT OF INTEREST

We have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Research data are not shared due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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