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

Running title: Young onset dementia: Service use, costs and satisfaction

Vasileios Stamou[16], Jenny La Fontaine[1], Heather Gage[2], Bridget Jones[2], Peter Williams[3], Mary O'Malley[47], Jacqueline Parkes[4], Janet Carter[5], Jan Oyebode[1]

[1]Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Richmond Road, Bradford, BD7 1DP, UK

[2] Surrey Health Economics Centre, Department of Economics, University of Surrey, Guildford, Surrey, GU2 7XH, UK

[3] Department of Mathematics, University of Surrey, Guildford, Surrey, GU2 7XH, UK

[4] Centre for Applied Mental Health Research, Faculty of Health and Society, University of Northampton, Northampton, NN1 5PH, UK

[5] Division of Psychiatry, Faculty of Brain Sciences, Maple House, University College London, London, W1T 7NF, UK

[6]Now at Manchester Metropolitan University

[7]Now at the University of West London

Corresponding author: Professor Jan Oyebode, Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Bradford, BD7 1DP, UK. J.oyebode@bradford.ac.uk; +44-7827976538

Word count: 3500

Acknowledgements:

This work was supported by the Alzheimer's Society under grant number 278 AS-PG-15b-034. The project was named after Angela, who received a diagnosis of YOD in her fifties. We gratefully acknowledge the significant contribution of the members of our Patient and Public Involvement Group and Steering Committee, as well as of the National Institute for Health Research, NHS and third-sector sites which facilitated study recruitment.

Disclosure of interest

We have no conflict of interest to declare.

Data availability

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

Young onset dementia: Service use, costs and satisfaction

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 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 young onset dementia services were more likely to receive support within the first six 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 three 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 hours per day caring; Median costs of health and social care, 3 months, 2018, were £394 (IQR £389 to 640).

Conclusions

Variation across diagnostic and post-diagnostic care pathways for young onset dementia 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 young onset dementia can access age-appropriate care.

Keywords (3-10)

Early onset dementia, Alzheimer's disease, frontotemporal dementia, rare dementias, caregivers, services, care pathways, service costs

Key points (up to 4)

- In the absence of detailed information on service use, costs and satisfaction for people with young onset dementia, a large national cross-sectional, self-report survey was conducted of people with young onset dementia and/or close supporters, receiving 233 usable responses.
- Nearly sixty percent of family members /supporters provided over 5 hours of care a day for the person with young onset dementia, 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 GP alone managed care on a regular basis was associated with lower satisfaction.
- Specialist young onset dementia 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.

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.

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.

Measures

The survey (Supplementary material: 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 elsewhere [19]). 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 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).

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.

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.

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 (Supplementary material, 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.

Results

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 hours 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>

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 supplementary material: S2, for detail).

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 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).

<TABLE 2>

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 three 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).

<TABLE 3>

Family care

Almost 60% of family members reported spending more than 5 hours per day supervising/helping the person with YOD and over 40% reported spending an additional 15 hours 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, IQR 2.5 - 8.3. The maximum hours per day of 25.5 were reported for three respondents where one family member provided 1-2 hours per day and other relatives/friends provided support 24/7.

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 >£8,000). 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 £1,000 over three months. Costs by survey completion pathway are shown in Supplementary material S4.

<TABLE 4>

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).

<TABLE 5>

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.

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.

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>

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 reported as co-ordinating their ongoing care, with only about 1 in 5 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 available [17] or there was no sign-posting information [22].

The survey confirmed suggestions from previous work [8-13] 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 elsewhere, [19].

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 £8,000 costs per family per three 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.

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 hours 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 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.

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.

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.

References

1. Zhu X-C, Tan L, Wang H-F et al. Rate of early onset Alzheimer's disease: a systematic review and meta-analysis. Ann Transl Med. 2015;3:38.

2. Prince M, Knapp M, Guerchet M et al. Dementia UK: Update. Second edition. London: Alzheimer's Society. 2014.

3. Greenwood N, Smith R. The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. Maturitas. 2016;92,102-109.

4. Holdsworth K, McCabe M. The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: a systematic review. Int Psychogeriatr. 2018;30:15-29.

5. Roach P, Drummond N. 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. J Psychatr Ment Hlth. 2014;21:889-995.

6. Spreadbury JH, Kipps C. Measuring younger onset dementia: What the qualitative literature reveals about the 'lived experience'for patients and caregivers. Dementia. 2019

7. Rossor MN, Fox NC, Mummery CJ, Schott JM, Warren JD. The diagnosis of young-onset dementia. The Lancet Neurol. 2010;9:793-806.

8. Sansoni J, Duncan C, Grootemaat P, Capell J, Samsa P, Westera A. Younger onset dementia: A review of the literature to inform service development. Am J Alzheimer's Dis Other Dement. 2016;31:693-705.

9. Armari E, Jarmolowicz A, Panegyres PK. The needs of patients with early onset dementia. Am J Alzheimer's Dis Other Dement. 2013;28:42-46.

10. Thorsen K, Dourado MCN, Johannessen A. Developing dementia: The existential experience of the quality of life with young-onset dementia–A longitudinal case study. Dementia. 2020;19:878-893.

11. Mayrhofer A, Mathie E, McKeown J, Bunn F, Goodman C. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. Aging Mental Health. 2018;22:933-941.

12. Westera A, Fildes D, Duncan C et al. Final report: Literature review and needs and feasibility assessment of services for people with younger onset dementia. Australian Health Services Research Institute, Wollongong, Australia, 2014.

13. Spreadbury JH, Kipps CM. Understanding important issues in young-onset dementia care: the perspective of healthcare professionals. Neurodegener Disease Manag. 2018;8(1):37-47.

14. O'Malley M, Parkes J, Stamou V, LaFontaine… J. Young-onset dementia: scoping review of key pointers to diagnostic accuracy. BJPsych Open. 2019;5(3). https://doi.org/10.1192/bjo.2019.36

15. Millenaar JK, Bakker C, Koopmans RTCM, Verhey FRJ, Kurz A, de Vugt ME. The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. Int J Geriatr Psychiatry. 2016;31(12):1261-1276. https://doi.org/10.1002/gps.4502

16. Rodda J, Carter J. A survey of UK services for younger people living with dementia. Int J Geriatr Psychiatry. 2016;31:957-959.

17. Cations M, Withall A, White F, Trollor JN, Loy… C. Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. PLoS ONE. 2017. 12(7): e0180935. https://doi.org/10.1371/journal.pone.0180935

18. Mayrhofer AM, Mathie E, McKeown J et al. Young onset dementia: Public involvement in co-designing community-based support. Dementia. 2020;19:1051-1066.

19. Stamou V, Fontaine JL, O'Malley M, et al. The nature of positive post-diagnostic support as experienced by people with young onset dementia. Aging Mental Health.2020. https://doi.org/10.1080/13607863.2020.1727854

20. [dataset] Oyebode J, Carter J, Parkes J, Gage H, et al. 2020; Angela project, Improving Support and Service Use Survey, available on reasonable request from j.oyebode@bradford.ac.uk or j.carter@ucl.ac.uk

21. Davis A, Hirsch D, Smith N, Beckhelling J, Padley M. A Minimum Income Standard for the UK in 2010. Joseph Rowntree Foundation. York; 2010

22. Pipon-Young FE, Lee KM, Jones F, Guss R. I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study. Dementia. 2012;11:597-616.

23. Wittenberg R, Knapp M, Hu B et al. The costs of dementia in England. Int J Geriatr Psychiatry. 2019;34:1095-1103.

24. Koopmans RT, Reinders R, van Vliet D, Verhey FR, de Vugt ME, Bor H, Bakker C. Prevalence and correlates of psychotropic drug use in community-dwelling people with young-onset dementia: the NeedYD-study. Int Psychogeriatr. 2014;26:1983-9.