


Establishing and sustaining high-quality services for people with young onset dementia: the perspective of senior service providers and commissioners

Jan Rachel Oyebode,¹  Jenny La Fontaine,¹ Vasileios Stamou,¹ Mary O'Malley,² Jacqueline Parkes,² and Janet Carter³

¹Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Bradford, UK

²Centre for Applied Mental Health Research, Faculty of Health and Society, University of Northampton, Northampton, UK

³Division of Psychiatry, Faculty of Brain Sciences, Maple House, University College London, London, UK

ABSTRACT

Objectives: We aimed to understand the facilitators to developing and sustaining high-quality services for people with young onset dementia (YOD) and their families/supporters.

Design: This qualitative study used semi-structured interviews with commissioners and service managers, analyzed using inductive thematic analysis.

Setting: A purposive sample of providers was selected from diverse areas and contrasting YOD services.

Participants: Eighteen senior staff from YOD services and two dementia service commissioners took part.

Measurements: For commissioners, key interview topics were experiences of commissioning YOD services, perceived facilitators or barriers, and how future guidance should be structured for ease of use. For service providers, key topics explored experiences of delivering YOD services; what was achievable or challenging; how the service was funded; how it linked with broader provision for YOD in the area; and how guidance should be structured.

Results: Recorded interviews lasted 30–40 minutes. Seven key facilitators to the development and sustaining of YOD services were identified: having knowledgeable, committed local champions; involvement of people living with YOD and family supporters; initial delivery within existing resources; partnership working within and between sectors; having a reflective, supportive organizational culture; gathering evidence of impact; and having wider support and guidance.

Conclusions: Improvements in provision for those with YOD and their families need to be built on understanding of service-level and interpersonal influences as well as on understanding of YOD itself. Our findings highlight a set of facilitators which need to be in place to establish and sustain high-quality YOD services that fit the local context.

Key words: early onset dementia, healthcare systems, qualitative research, service delivery, young onset dementia

Introduction

Young onset dementia (YOD; onset <65 years) has an estimated global prevalence of 119 per 100,000 of those aged 30–64 years (Hendriks *et al.*, 2021). Although accounting for only 7.5% of dementia in

the United Kingdom (UK; Carter, 2022), UK numbers are estimated at over 70,000. The distinctive needs of people with YOD include the diversity of presentations and diagnoses, which mean individuals may need specialist support for visual, language, or behavioral problems as well as memory difficulties (Carter *et al.*, 2018). Those diagnosed are more likely to be in employment (Egdell *et al.*, 2021; Ritchie *et al.*, 2018), have financial outgoings, and have dependent children, young people, or elderly parents (2013; Withall, Koopmans *et al.*, 2013). In this context, age-appropriate services are vital.

Correspondence should be addressed to: Jan Oyebode, Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Horton A Building, Richmond Road, Bradford, BD7 1DP, UK. Phone: (+44) 7827976538. Email: j.oyebode@bradford.ac.uk. Received 09 Sep 2022; revision requested 27 Jan 2023; revised version received 28 Mar 2023; accepted 27 Apr 2023. First published online 21 September 2023.

Sound evidence on best practice remains limited. Consultation work has led to proposals about attributes needed for good YOD services. Services should be co-designed with people with YOD and their families (Hutchinson *et al.*, 2020; Mayrhofer *et al.*, 2020); streamline diagnostic processes; be integrated; provide a named point of contact; be individualized; be outcomes-oriented; provide appropriate information about diagnosis, family support, legal and financial advice; and provide access to advanced care planning and palliative care (Fox *et al.*, 2020; Mayrhofer *et al.*, 2021; Sansoni *et al.*, 2016). While such attributes are also important in services for older people, the specifics vary due to context and nature of YOD, for example, appropriate care may require specialist speech and language therapy or a financial advisor.

Complementing these recommendations, some publications describe what is provided in practice. The Netherlands' approach consists of a national "knowledge center" linked with large regional healthcare providers, which in turn support smaller local support services (Bakker *et al.*, 2022). Other approaches have been built around a diagnostic hub in a medical setting (Loi *et al.*, 2022); charitable community services (Mayrhofer *et al.*, 2020; Ottoni *et al.*, 2021), or a balanced integrated model across health and charitable sectors (Hussey, 2016). Bakker *et al.* (2022) comment that organizational collaboration, cohesion, and mutual learning are vital.

Few specialist YOD services, as opposed to "all-age" dementia services, have been evaluated, but it has been found that specialist services provide the most effective support (Stamou *et al.*, 2021). Stamou *et al.* (2022), integrating data from people living with YOD about service experiences, conclude person-centeredness, functional consistency, and organization consistency are the core features of successful YOD services. Yet, in most countries, formal YOD services are patchy, un-coordinated, and often disestablished due to short-term funding (Mayrhofer *et al.*, 2018; Rodda and Carter, 2016; Sansoni *et al.*, 2016).

Given the well-established needs of those with YOD and the increasing evidence that specialist YOD services are effective, there is a need to explain the continuing lack of such services. Possible barriers include low prevalence (Withall, 2013), costs (Bakker *et al.*, 2022), and the challenges of providing services for rare conditions, especially in rural areas (O'Connell *et al.*, 2014). The aim of the work described here was to understand the facilitators to establishing and sustaining services for people with YOD and their families/supporters.

Methods

We adopted a "subtle realist" position (Hammersley, 1992) that the phenomenon being explored could be revealed through accounts of people's direct experiences, while acknowledging that each researcher would bring a unique perspective to interviewing and analysis due to the influence of their own experiences. Qualitative semi-structured interviews were conducted and then analyzed using reflexive thematic analysis (Braun and Clarke, 2021a). Ethical approval was received from the English Health Research Authority (South Central Berkshire Research Ethics Committee, REC ref.: 17/SC/0296).

Participants

Each participant needed to be a senior manager or clinician or a commissioner of a YOD service. A proportion of UK national health service (NHS) funding is devolved to more local levels where it is used by NHS "commissioners" to "commission" services for local populations, including for people living with dementia.

Recruitment

We aimed to gather views from 20 participants, a suitable sample size to give rich insights and provide trustworthy themes (Braun and Clarke, 2021b). Sampling was purposive. Five areas were identified with different levels of resourcing and types of provision (i.e. services primarily provided by an NHS organization vs services primarily provided by a charitable community organization). The research fellow (RF) approached potential participants in each area in the NHS and community sectors. For further variation, we also approached staff in one private national provider of live-in care for people with YOD and one tertiary neurology diagnostic service. The RF shared an information sheet and arranged a face-to-face, phone, or online interview with those willing to participate. Written informed consent was obtained on the day of the interview, with consent forms returned via post if the interview was remotely conducted.

Data collection

Interviews focused around open questions on commissioning or providing YOD services and enablers and barriers to provision (see supplementary material for interview guides). Interviews were conducted by the RF between February and April 2019, audio-recorded, transcribed verbatim, and anonymised. The RF was an experienced qualitative

researcher. She had previously met a minority of the participants through her work as a senior nurse, prior to moving into research. To promote reflexivity, the RF made field notes and discussed the interviews with two of the research team. Anonymised transcripts were uploaded to N-Vivo to assist analysis. This paper focuses on service facilitators in order to suggest solution-focused approaches to service improvement. Barriers will be reported elsewhere.

Analysis

The principles of reflexive thematic analysis were followed to achieve contextualized understanding (Braun and Clarke, 2021a). The RF read and re-read the transcripts before attaching codes to meaningful text segments, using descriptive rather than interpretive coding, to fit with the aim of the research (Braun and Clarke, 2022). The RF then clustered codes into sub-themes and themes. Throughout analysis, regular discussions took place between the RF and two other researchers to check for bias and ensure we were capturing participants' experiences. The themes were shared with the wider project team, as well as three people living with YOD and three family supporters from the project's experts-by-experience advisory group, to check plausibility and relevance.

Results

Of 30 people approached, 7 failed to respond (four community organization staff, three commissioners), 1 community organization manager declined, and 2 commissioners sent brief email responses not included here. Twenty participants took part in interviews lasting 30–40 minutes: 18 service providers (8 NHS, 9 community sector, 1 with a dual affiliation) and 2 commissioners. At least two people took part from each of the five geographical areas (range 2–5); one took part from the live-in carer service, and two from the tertiary neurology service (see details in Table 1).

Seven key facilitators were found. Having a knowledgeable, committed local champion seemed universal in establishing provision. Involvement of people living with YOD and family supporters facilitated service development by overcoming ignorance or misconceptions. It was also helpful when initial services involved reconfiguration of existing resources rather than requiring new funding. Partnership working across agency and service boundaries facilitated the building of seamless

services. A reflective and supportive organizational culture was important to develop and retain knowledgeable and skilled staff. Gathering evidence of impact facilitated support from senior management and commissioners. Finally, participants felt being part of wider networks and/or having specific guidance could be a key stimulus to further development. Each theme is described below.

Knowledgeable committed local champions

Specialist YOD teams were commonly initiated by experienced clinical staff who championed and took actions to kick-start service development. They were knowledgeable about what was needed, had tenacity to persist and, crucially, were prepared to act on their own initiative. In one area, for example, the key clinician described a “eureka moment” when she realized that she could exercise her initiative to start the YOD service. She explained:

We had been meeting as a young onset steering group literally for years and then I saw this programme called Can Jerry Robinson Fix the NHS. I was looking at it thinking that is us, we are continuously talking about this, waiting for a load of cash to drop from the money tree to help us develop this service when actually we could change tomorrow. So, I went in the following day and I went: “I have seen this programme, that’s us, we are just talking about it, why don’t we just change what we do, why do they [i.e. younger people referred to the generic dementia team] have to go to everybody, why couldn’t they go to one CPN, or one . . . why? We set that up, we could change that. (SP10)

The initiative taken by this experienced clinician was the first step in establishing what had since become a successful multi-disciplinary YOD team:

. . . fast forward another three or four years, five years maybe, and the young onset team won the Trust prize of the year. So, to be honest, absolutely, if we hadn’t have had the vision and the ‘right we’re going to do this’, but also the tenacity to carry on under quite a lot of heavy criticism, we wouldn’t have the service we’ve got now. (SP10)

Involving people with YOD and carers

Most participants highlighted the positive benefits of involving people living with YOD and their families in service development, to persuade commissioners and senior members of NHS Trusts to support the need for specialist services and to inform the way services should be shaped on an ongoing basis.

Inviting people with YOD to tell their stories to older people’s service managers was reported as making a huge difference to their recognition of the need for specialist services:

Table 1. Details of services and roles of the participant sample ($N = 20$)

AREA	ROLE OF PARTICIPANT	IDENTIFIER
1. NHS multi-disciplinary YOD team, linked with community charitable providers. Rural area.	<ul style="list-style-type: none"> • Joint health and social care commissioner • NHS YOD team manager/clinician • Directors of charitable provider of community support, including for YOD 	Com1 SP4 SP2, SP5
2. NHS multi-disciplinary YOD team, linked with community charitable providers. Urban area. No specially commissioned service but organized as part of a general all-age dementia contract.	<ul style="list-style-type: none"> • NHS YOD team manager/clinician • Charitable carer support organization, including for YOD 	SP1 SP3
3. NHS consultant-led YOD team, covering one patch in a large NHS Trust. Urban area.	<ul style="list-style-type: none"> • NHS YOD consultant psychiatrist • Organiser self-organised support group for YOD 	SP7 SP16
4. NHS multi-disciplinary YOD team, linked with community charitable providers, covering one patch in a large NHS Trust. Mixed urban/rural area.	<ul style="list-style-type: none"> • Commissioner • YOD and rare dementias strategic lead for the area • YOD multi-disciplinary team lead • YOD neuropsychologist • Community group for people with YOD • NHS YOD consultant/YOD charity Trustee 	Com 2 SP10 SP8 SP13 SP6 SP9
5. YOD service, predominantly situated in third sector. No specially commissioned NHS service but set up from existing resources, with one YOD lead in each of 6 all age teams, 2 part-time Admiral nurses and one consultant with a special interest.	<ul style="list-style-type: none"> • Charity senior staff member, domiciliary care provider for YOD • NHS YOD specialist Nurse • Admiral nurse 	SP18 SP12 SP11
6. Tertiary diagnostic service in neurology, consisting of a consultant with a special interest and a newly funded Admiral Nurse. South of England.	<ul style="list-style-type: none"> • Consultant neurologist • Admiral nurse 	SP15 SP14
7. Private national provider of live-in care for people with YOD.	Chief executive	SP17

And I think because we've managed to get higher people in the Trust along to those meetings that hearing people with a young onset dementia does have a big impact on them, it does have a massive impact, because it's something without their experience of them. They work in services for older aged people, and anybody young with dementia is outside of their experience. [...] So that has been, that has really helped them to go along with us. (SP8)

This approach also helped convince commissioners of the service needs of people with YOD:

At the end of the day if you're wanting people to commission a service, it's very difficult with younger people because commissioners understand the numbers game, and you're forever trying to say but this is a small number of people but with very high unmet need. So, I think it was through listening to carers and people with dementia, that helped us describe the service that was needed, so I think that was quite important. I think getting the ear of a right commissioner is really important. (SP9)

Several participants regularly consulted service user groups about aspects of provision. The leader of a YOD team in a rural area gave an example about how consultation could influence both local services and input to national discussions:

There was [...] a small peer group specifically for people living with a diagnosis, again met once a month, and the group very much decided that they wanted it purely to be for people living a diagnosis and not for family carers, and they provided a lot of really valuable input into changes that should be made, what services should ideally look like, were able to make comments on documents, on both local things but also on people contacting me about national things and the group would make comments on documents and things. (SP4)

Once established, consultation channels could be used to shape services on an ongoing basis. For example, the team leader quoted above described specific examples of small user-led changes that made local community services more dementia friendly:

A local leisure centre came to talk and they [the YOD peer group] made some suggestions, and as a result of that a swimming group for people living with dementia was set up. There were small adaptations to magnetic... people could have magnets for their lockers so they could put a magnet on their locker to highlight where their locker was when they had been swimming. (SP4)

One issue raised by some participants was the need to hear the voice of more diverse groups when planning services. The manager of a well-established

YOD charity was aware wider consultation was needed:

It feels to me like take up from the [YOD services] seems to be a bit lower in [place], and that's probably our most diverse population in [place]. So, I don't know, we're still working on that as to whether there's more education, whether the offer needs to be different to make it more culturally acceptable. I haven't got an answer as to why, but that seems to be something that we need to be doing more work to understand. (SP12)

Initial delivery within existing resources

A further facilitator that enabled service startup was to find a way of re-aligning existing resources to provide a YOD-specialist element. Most commonly, in the UK, dementia services sit within mental health services for older people. So, finding a way of organizing a defined YOD pathway within all-age dementia services was a means of offering tailored diagnosis within existing resources. One creative approach was to set up a network of YOD-interested clinicians as a "virtual service":

They [people with YOD] were part of our service, and obviously we're a National Health Service funded service, we're an older people's mental health service where dementia has always traditionally sat. So a lot of these people were part of our workload, but we made the conscious decision to get together a group of people who had a particular interest in working with people with a young onset dementia, and some level of experience, and so we set up what we called a virtual team, so we didn't have any extra funding at this point, we just decided to reconfigure the resources that we had differently. (SP8)

Other specialist services were initially set up as pilot projects to produce evidence that would convince commissioners of the need for further support, sometimes by identifying as part of a wider specialist grouping such as rare dementias:

The first bit of additional funding that we have had has come very recently because we have expanded to be a rare . . . our young and rarer dementia team, so now since January of this year we have got some additional funding for my post to be a full time clinician and manager, and we've got an additional support work post, and so we've expanded to take people with rarer dementia of any age as well as all the people with a young onset dementia. (SP8)

Pilot projects were sometimes initiated via community organizations which were less constrained by NHS rigidity:

I think what was gained from those pilots was some evidence of the benefits to carers or people with dementia [. . .]. It was about I suppose maybe something about charities and having that flexibility to develop as the need takes them and not having the constraints of always having to have a permanent funding secured before you can go forward. (SP12)

Partnership working

A further powerful facilitator was the collaborative, cross-agency working which enabled design of local care pathways to ensure continuity and coordination of care. A service commissioner spoke about the importance of bringing organizations together:

I think for me it's probably more having the strategic oversight, because everybody delivers an element of the dementia care, and for me it's really making sure that from early awareness raising until end of life everything is covered, that things are seamless for patients. So it's probably making sure that the whole pathway is delivered well, and I think my role as well was to bring the various organisations together. (COM2)

The importance of partnership across many combinations of services and sectors was mentioned by almost all participants (see Table 2 for examples) and underpinned formation of service strategy as well as effective support for individuals with YOD and their families.

As well as showing an array of partnerships, these examples also illustrate mechanisms that facilitated collaboration, including human relationships and flexibility, as well as formal mechanisms, for example, to achieve unified record-keeping. Establishing collaborations was often recounted as a difficult task that required determination and persistence:

It's about chipping away a lot of the time. It's about people . . . each service has their own criteria as how they would get involved, so it's a lot of persuasion a lot of the time and just again having a face-to-face profile with people. I think you have much more clout in terms of getting somewhere if people are actually seeing you face to face, [. . .], that's why I've always tried to find someone within a service who I start that engagement process with and then I get to know other people and they start to spread the word [. . .] you just need to keep yourself out there, and keep reminding people. (SP11)

This theme demonstrates the emphasis placed on collaborative working, which appears essential in enabling pathways to be developed to ensure timely diagnosis and appropriately coordinated support. Once established, ongoing contact and inter-agency meetings were also vital to enable areas to set up systems to share information and promote cross-boundary working.

Reflective, supportive organizational culture

As most health professions have little exposure, if any, to YOD issues during training, participants commonly described building the capacity of resilient YOD-aware, YOD-skilled practitioners, through an organizational culture that was reflective, supportive, and fostered continuing professional development. It seemed particularly helpful when

Table 2. To show collaborative partnerships that facilitated specialist YOD services

PARTNERSHIP	ILLUSTRATIVE QUOTATION
Between commissioners and providers	<i>So I think the approach is really about partnership working, and for me as a commissioner more listening to what people think is important, and it's almost an orchestra. You direct and try to be as inclusive and listening as well as possible, with trying to keep the common themes and priorities a bit going. [...] so that really helps as well if you have got people close by and everybody knows each other, then it's much easier to commission services, to stimulate partnership. (COM2)</i>
Between neurologists and memory clinics in mental health services	<i>So we've given the GPs guidance, so if very young, if neurological symptoms, if this, then go to neurology, and if it's more, seems related to, I guess more the straightforward but younger if that's possible, they would refer straight to the memory clinic. But in a sense if that doesn't happen, because we have good lines of communication with the neurologists, we can fast track to each other pretty easily. [...]. So I think the talking, getting to know the neurologists and getting to know us, so it's you know the personalities rather than just emails is quite important as well, making those people connections. (SP9)</i>
Between diagnostic and post-diagnostic support services	<i>What we have is a seamless model of working with the charity [...]. So once people have got their diagnosis and they have had their post-diagnostic information and counselling there is something else that's age specific for them to engage with which is the charity in the main, and where we've worked as a Trust with the charity is to develop honorary contracts for them, [...] that enables them to actually record directly onto our patient clinical record. So there that's where the seamless working comes in. (SP12)</i>
Between different sectors (e.g. health, social care, employment)	<i>I quite often will help support people with Social Services, help them understand how the system works, I will contact Social Services myself to explain maybe how to approach someone to do an assessment or to offer to do a joint assessment, to be there to talk people through, [...] I have supported people maintaining their work where they have still been in work by attending HR sessions with them or occupational health sessions, or actually providing regular meetings with support workers within their workplace to enable them to continue. So it's very flexible and fluid in terms of what we do or how I link up with other people. (SP11)</i>
Between community organizations and NHS sectors	<i>... because she was at high risk of suicide [...], what we do is we work really closely with the mental health team, so every time we see her we actually do the app, we fill all that in, but we also email over an encrypted file some notes so they can then upload them onto the NHS system, so we're all singing from the same page, and if we've got any concerns about her at all we just call the mental health practitioner and just let her know that we think her mood has changed or her cognition has changed. (SP18)</i>
Between services and volunteer fund raisers	<i>For example, [...] a local working men's club, has just done a whole year of fundraising for us, so that's massive, we raised our profile and we've attended those fundraising events, and they have attended our events. [...] So really it's just being part of a community and raising the profile in the community. (SP8)</i>

there were support systems that were responsive and offered opportunities for non-judgmental, case-oriented discussions whether with peers or line managers:

I think when you're working with younger people it can be emotionally and physically draining at times, so I think having a good rapport with the team members really helps because then they feel that they can actually come in, pop into the office and call or text or ask for help, and having that culture where if things go wrong then things do happen and things do go wrong but no one is going to get blamed for it. It's about how we look at what we could have done differently. (SP18)

This type of back-up was highly valued, even by very experienced staff. In this case, a person with over 20 years of experience spoke of how talking to the team manager helped her deal with her own emotional responses:

I text her and say can I have a chat at some point this afternoon, for instance. She will make space or rejig things or whatever. She knows that if I'm asking, if I'm telling her that I need to talk about something she knows that it must be bad, [...] I am ringing her because I've potentially had a really awful situation, like for example a couple of weeks ago I went to meet with a carer, her husband had his diagnosis that week aged 47, and she'd

given birth to their first child in the same week, so that as you can imagine was just mind blowingly tragic really. (SP3)

In addition, modeling or coaching was helpful in enabling staff to develop the skills needed to work effectively:

So she's given me examples of where one of the personal assistants, their communication with somebody with young onset Alzheimer's disease was too much information, and they were out-pacing them, and [experienced member of staff] said she took him to one side and said, "What you need to do is, he can't follow that, you just need to go much slower," and she told him and then was modelling herself with this man, and she said he was so much better. (SP10)

Formalised support systems were described too, particularly supervision from those with expertise.

Gathering evidence of impact

Service providers spoke about how important it was to continually gather evidence regarding service impact, to defend what could otherwise be perceived as elitist, expensive services. Evidence on reduction in crises and the associated cost savings was seen as especially influential:

Very rarely does somebody with a young onset dementia get admitted to one of our psychiatric wards when they are at home. That has definitely fallen, because they're not coming in at crisis point. We're not firefighting, we are anticipating these things before they happen, so we've got a really good record of people either dying at home, if that's what the person and the carer wants, or going into care seamlessly and not having to have a hospital admission. (SP3)

However, a wide range of evidence was seen as helpful in keeping the support of commissioners of services, as illustrated here by a specialist nurse:

So the combination of the qualitative stuff, the actual feedback, quotes from carers, but also the stats, health economics, that side of things I think, and actually the charity developed a short video, [...]. So I think it was probably a combination of somebody really knowledgeable in the field being able to articulate the different challenges that people with young onset dementia and their carers face but then using a few different modes of evidence, so that depending on what people are looking whether they're looking for the pound side of things or whether they are looking for the patient gain side of things, they would be influenced by it. (SP12)

This was echoed by commissioners as it provided them with justification for using some of their resources for YOD:

So they [case studies] showed the benefit for the person, the families for this family to have a support worker, to have those peer support groups. So I think if

they can show the evidence of quality of life and preventing crisis situations [. . .] that helps to build the case, and for me to say it's okay to continue, it's a good way of spending our resources. I think for the help, because although it's a small group it's still a substantial group, it's about 40/50 people we've got, so it's still it's not one or two. (COM 2)

Wider support and guidance

YOD services are usually developed in an ad hoc way and those running them spoke of feeling isolated from others. Participants proposed that having more links with other services and official guidance would help to support specialist service development and sustainability.

One service provider spoke of the value that could be obtained if examples of what works well were collated:

Examples of what is working well elsewhere would be helpful, some examples of different types of support for the person with dementia on the families and what people have felt has been useful and worked, and I don't know, maybe just some examples of how organisations statutory and voluntary can work together and enhance what each other is doing. (SP3)

There was a view that if these were included in guidance issued by well-respected bodies, this would reinforce the position of those trying to establish YOD services.

I guess there's not much of a clear national consensus around the need for this, and really specific services seem rarer than they used to be, so any support from research, professional bodies, national guidance around how we best meet the needs of younger people with dementia would be important. [...] I think something that specifies what the needs are and how those are best met rather than just saying something should be done and this is why, I think it needs to be more concrete than that. (SP1)

A further suggestion was that demonstration sites could be very helpful:

Key services around the country that seem a bit ahead of the game, maybe having them as contact points, because I think it is quite an isolated, and I know speaking to other people who have worked in young onset dementia it is quite isolated, so having those links to probably more developed services would actually be a really good step in the right direction because you could go and see them, make links with them, ask them how they developed things, and learn from . . . I found that really helpful learning from others. (SP4)

Also having access to good quality training would help those wishing to develop services:

I think training is a big issue because there's not really an awful lot out there particularly on rare types of

dementia, so having someone onsite that could help deliver that I think would be useful for future organisations. (SP18)

Discussion

Our data suggest a constellation of facilitators is key to establishing and sustaining YOD services. Some of these have been highlighted previously, particularly the need for “involvement of people living with YOD and their families” and for “integrated working”, and the theme “reconfiguring existing services” addresses a previously cited barrier to establishing services (Fox *et al.*, 2020; Hutchinson *et al.*, 2020; Mayrhofer *et al.*, 2020; Sansoni *et al.*, 2016). “Having a knowledgeable committed champion”, having “a learning culture,” and “gathering evaluative evidence” have not been prominent in previous literature.

Authentic involvement of those with direct experience was key to inform provision and raise awareness and empathy in those with the power to establish new services. Previous consultation exercises have also suggested involvement is important (Hutchinson *et al.*, 2020; Mayrhofer *et al.*, 2020). Equally, integrated provision has been widely recommended (Mayrhofer *et al.*, 2021; Sansoni *et al.*, 2016) and found to be important in YOD services (Bakker *et al.*, 2022; Stamou *et al.*, 2021). In our analysis, this theme was very widely supported. The analysis showed that it required persistence and persuasion to achieve involvement and collaboration and establishing trusting relationships was fundamental. Involvement of people living with YOD was often initiated by finding and attending a place where those with YOD were already meeting. Partnership working was found to be complex, requiring open-mindedness and flexibility to bring about the conditions, such as shared record-keeping, that would allow joined-up provision. Services were not brought together under one organization but worked together, finding ways to overcome organizational differences. Collaborative relationships facilitated agreement on a clear YOD care pathway, something that is essential for continuity of care.

A further facilitator was initiating YOD services through reconfiguration of existing resources. This avoided having to make a case for additional funding (Bakker *et al.*, 2022). Initial developments were often modest, such as starting with a virtual service network, and often started in the community sector, well known for being able to innovate as there is more freedom to act than in the statutory sector (Smith, 2021).

In every case in our study, committed and knowledgeable champions were the catalyst for

development. Champions were experienced senior clinicians who could take autonomous steps to initiate a service or convince management it was needed. It is well recognized in organizational development work that change is often started by champions (Shea, 2021). We found some needed to wake up to the possibility that they *could* exercise agency to initiate a service, a process often provoked through the frustration of waiting for others.

A further facilitator was having a reflective and supportive organizational culture, so staff could develop their expertise and feel sufficiently nurtured to continue to work in emotionally demanding roles. Notably, the benefits of a culture of mutual learning were also mentioned by Bakker *et al.*, (2020). Most pre-registration professional training includes little about dementia, let alone YOD (Pulsford *et al.*, 2007); therefore, staff gain expertise through continuing professional development, supervision, modeling, and coaching. There has been considerable emphasis on organizational cultures in health and dementia care in recent years (e.g. Caldwell *et al.*, 2012) and our findings resonate with this.

Finally, participants’ accounts suggested senior staff and commissioners needed to be provided with evidence that YOD was distinctive enough to warrant “special” services, with cost savings and case studies being cited as effective ways to show evidence of impact. Hearing about lived experience through case studies may help those who have little direct contact with YOD, to have greater empathy and appreciation of service needs, echoing the use of “narrative medicine” in healthcare training (Charon and Montello, 2004; Baillie *et al.*, 2016).

Having wider support and guidance was identified as a facilitator that would further guide the development of services, rather than having to set their own benchmarks and standards. This was the only theme to be aspirational rather than based on real-life experiences. The UK Memory Services National Accreditation Programme (Abhayaratne *et al.*, 2020) contains three YOD-specific standards but is voluntary and narrow rather than holistic in focus. Development of schemes similar to the Netherlands’ hallmark could be a way of offering providers more guidance on the standards for which they should aim.

Our study has a number of limitations. We did not gain a perspective from those who have not commissioned or established YOD services. This could contribute valuable information about why such services are not more widespread. We relied on retrospective accounts and, in addition, we were only able to include two commissioners. However, we included diverse providers and undertook rigorous analysis to identify common facilitators to establishing and sustaining YOD services. One

strength of the study lies in the attention paid to real-life experiences, complementing studies based on consultation about what services should ideally provide.

In conclusion, we recommend that the starting points of YOD-service development are to find the experienced professional who is in the best position to change provision and locate people with YOD and families who can be consulted. Reconfiguration of existing services and concerted attempts to build collaborations and map a YOD pathway would be the following steps. Building or maintaining a supportive culture is crucial to develop expertise and retain staff, and gathering evaluative data is vital to convince managers and commissioners to sustain provision. Further research is needed on the outcomes of specialist YOD provision. However, this study contributes to knowledge on how to establish the specialist services needed by people living with YOD.

Conflicts of interest

None.

Description of authors' roles

All authors were involved in critical revisions and approval of the manuscript. JC, JP, JO, JLF, and VS were involved in designing the study. JLF conducted all data collection. JO, JLF, and VS were involved in everyday decisions regarding data collection, analysis, and interpretation. JO drafted the paper.

Acknowledgements

This work was supported by the Alzheimer's Society under grant number 278 AS-PG-15b-034. We gratefully acknowledge the significant contribution of the members of our Patient and Public Involvement Group and Steering Committee.

Supplementary material

To view supplementary material for this article, please visit <https://doi.org/10.1017/S1041610223000443>

References

- Abhayaratne, C., Blanchard, E., Grealley, S. and Rogers, S.** (2020). *Memory Services National Accreditation Programme Standards for Memory Services* (7th ed.). London: Royal College of Psychiatrists.
- Baillie, L., Sills, E. and Thomas, N.** (2016). Educating a health service workforce about dementia: A qualitative study. *Quality in Ageing and Older Adults*, 17, 119–130.
- Bakker, C., Verboom, M. and an Koopmans, R.** (2022). Reimagining postdiagnostic care and support in young-onset dementia. *Journal of the American Medical Directors Association*, 23, 261–265.
- Braun, V. and Clarke, V.** (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21, 37–47.
- Braun, V. and Clarke, V.** (2021b). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13, 201–216.
- Braun, V. and Clarke, V.** (2022). *Thematic Analysis: A Practical Guide*. London: SAGE.
- Caldwell, C., Dixon, R. D., Floyd, L. A., Chaudoin, J., Post, J. and Cheokas, G.** (2012). Transformative leadership: Achieving unparalleled excellence. *Journal of Business Ethics*, 109, 175–187.
- Carter, J. E., Oyeboode, J. R. and Koopmans, R. T. C. M.** (2018). Young-onset dementia and the need for specialist care: A national and international perspective. *Ageing & Mental Health*, 22, 468–473.
- Carter, J.** (2022). Prevalence of all cause young onset dementia and time lived with dementia: Analysis of primary care health records. *Journal of Dementia Care*, 30, 1–5.
- Charon, R. and Montello, M.** (2004). *Stories Matter: The Role of Narrative in Medical Ethics*. New York: Routledge.
- Egdell, V., Cook, M., Stavert, J., Ritchie, L., Tolson, D. and Danson, M.** (2021). Dementia in the workplace: Are employers supporting employees living with dementia? *Ageing & Mental Health*, 25, 134–141.
- Fox, S., Cahill, S., Kilty, C. and McGowan, R.** (2020). *Younger Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways*. Tullamore: The National Dementia Office.
- Hammersley, M.** (1992). *What's Wrong with Ethnography?* London: Routledge.
- Hendriks, S. et al.** (2021). Global prevalence of young-onset dementia: A systematic review and meta-analysis. *JAMA Neurology*, 78, 1080–1090.
- Hussey, J.** (2016). Younger people: An innovative partnerships. *Journal of Dementia Care*, 24, 20–22.
- Hutchinson, K., Roberts, C., Roach, P. and Kurrle, S.** (2020). Co-creation of a family-focused service model living with younger onset dementia. *Dementia*, 19, 1029–1050.
- Koopmans, R. T. et al.** (2013). Services for people with young onset dementia. In: H. De Waal, C. Lyketsos, D. Ames and J. O'Brien (Eds.), *Designing and Delivering Dementia Services* (pp. 33–45). Oxford: John Wiley & Sons Ltd.
- Loi, S. M., Walterfang, M., Kelso, W., Bevilacqua, J., Mocellin, R. and Velakoulis, D.** (2022). A description of the components of a specialist younger-onset dementia service: A potential model for a dementia-specific service for younger people. *Australasian Psychiatry*, 30, 37–40.
- Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F. and Goodman, C.** (2018). Age-appropriate services for people

- diagnosed with young onset dementia (YOD): A systematic review. *Ageing and Mental Health*, 22, 933–941.
- Mayrhofer, A. M. et al.** (2020). Young onset dementia: Public involvement in co-designing community-based support. *Dementia*, 19, 1051–1066.
- Mayrhofer, A., Shora, S., Tibbs, M., Russell, S., Littlechild, B. and Goodman, C.** (2021). Living with young onset dementia: Reflections on recent developments, current discourse, and implications for policy and practice. *Ageing & Society*, 41, 2437–2445.
- O’Connell, M. E. et al.** (2014). Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early-onset dementias. *Dementia*, 13, 382–395.
- Ottoboni, G. et al.** (2021). Needs-appropriate services for people with young onset dementia: The perspectives of healthcare professionals. *Dementia*, 20, 2725–2745.
- Pulsford, D., Hope, K. and Thompson, R.** (2007). Higher education provision for professionals working with people with dementia: A scoping exercise. *Nurse Education Today*, 27, 5–13.
- Ritchie, L., Tolson, D. and Danson, M.** (2018). Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers. *Ageing & Society*, 38, 2146–2175.
- Rodda, J. and Carter, J.** (2016). A survey of UK services for younger people living with dementia. *International Journal of Geriatric Psychiatry*, 31, 957–959.
- Sansoni, J., Duncan, C., Grootemaat, P., Capell, J., Samsa, P. and Westera, A.** (2016). Younger onset dementia: A review of the literature to inform service development. *American Journal of Alzheimer’s Disease & Other Dementias*, 31, 693–705.
- Shea, C. M.** (2021). A conceptual model to guide research on the activities and effects of innovation champions. *Implementation research and practice*, 2, 1–13.
- Smith, D. H.** (2021). The impact of the voluntary sector on society. In: J. Ott and L. Dicke (Eds.), *The Nature of the Nonprofit Sector* (pp. 84–93). New York: Routledge.
- Stamou, V. et al.** (2021). Services for people with young onset dementia: The ‘Angela’ project national UK survey of service use and satisfaction. *International Journal of Geriatric Psychiatry*, 36, 411–422.
- Stamou, V. et al.** (2022). Helpful post-diagnostic services for young onset dementia: Findings and recommendations from the Angela project. *Health & Social Care in the Community*, 30, 142–153.
- Withall, A.** (2013). The challenges of service provision in younger-onset dementia. *Journal of the American Medical Directors Association*, 14, 230–232.