Understanding the Needs of People With Rare Dementias and Recommendations for Improving Post-diagnostic Care: ‘There Is No Such Thing as One Size Fits All’

Clarissa Giebel (✉ Clarissa.giebel@liverpool.ac.uk)

University of Liverpool

Jacqueline Cannon

Wigan Dementia Action Alliance

Sandra Smith

NIHR ARC NWC

Anna Pearson

North West Boroughs NHS Foundation Trust

Research Article

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Abstract

People with rare dementias such as Lewy Body dementia show different symptoms to those with Alzheimer's dementia. Due to the large proportion of people with Alzheimer's dementia, most services are designed to support their needs and often neglect those of people with rarer dementias. The aim of this study was to understand the needs of people with rare dementias and their families to develop targeted support. Two care professional focus groups were held in the North West of England. Focus groups lasted up to 60 minutes and were subsequently transcribed and analysed via thematic analysis. One former carer for her husband with a rare dementia was an active member of the project team and helped design the interview schedule, interpret and disseminate the findings. 18 dementia care professionals took part. Thematic analysis generated six themes: (1) Complex needs unsupported; (2) Reluctance to approach services; (3) Lack of service adaptation to both people living with dementia and carers; (4) Lack of communication between service providers; (5) Environment of service provision; (6) Funding issues. As opposed to suggesting new types of social activities, focus groups identified significant barriers in approaching and using post-diagnostic for those affected by a rare dementia, as well as inequalities in access to care services. There are various personal and service barriers for people with rarer dementias and unpaid carers to accessing and using post-diagnostic services. Future implementation work needs to adapt services and identify ways in which to overcome barriers in approaching services.

What Is Known About The Topic

What is known about the topic:

- People with rare dementias have specific needs that differ from those with Alzheimer's disease dementia
- People with rare dementias often feel left out of dementia services
- There seems to be very little tailored support for people with rare dementias and their carers

What this paper adds:

- This study sheds light on different reasons why people with rare dementias and their carers rarely seek out services, including funding issues
- Service provision appears to be very patchy and a postcode lottery, with some areas offering more specific services, and others failing to do so
- Given the nature of many rare forms of dementia, people with dementia and carers would often prefer one-to-one support as opposed to group support

Background

Alzheimer's dementia, the most common form of dementia, affects an estimated 62% of all people with dementia (Alzheimer's Society, 2014). The remainder, an estimated 320,000 people, experience a rarer

form of dementia, which can be a barrier to receiving the right form of care and support due to the various needs of each different dementia subtype.

Considering the different subtypes of dementia, including Lewy Body dementia, Parkinson's disease dementia, vascular dementia, and semantic dementia, to name but a few, each different dementia subtype is characterised by varied symptoms (Crutch et al., 2018; McArdle et al., 2017; McGuinness et al., 2010). This includes variations in performing everyday activities such as washing or preparing a meal (Giebel et al., 2017), different cognitive profiles (Gurnani & Gavett, 2017), different behavioural symptoms such as agitation or lack of inhibition (Moheb et al., 2017), as well as language difficulties (Volkmer et al., 2019). As a result, people with for example vascular dementia experience different needs to those with Alzheimer's dementia (Giebel et al., 2018), as people with vascular dementia are found to be more impaired when performing tasks of medication management and going grocery shopping. Also, people with behavioural variant fronto-temporal dementia are more impaired overall on daily activities than people with Alzheimer's dementia, and show a faster decline in using the stove and travelling (Giebel et al., 2020a).

However, with the majority of people with dementia being diagnosed with Alzheimer's dementia, many existing services, such as memory cafes, carer support groups, or specific activities, such as cinema clubs or gardening activities, are more likely to be targeted at people with Alzheimer's dementia. For example, people with behavioural variant fronto-temporal dementia experience many behavioural symptoms, such as lack of inhibition or aggression (Moheb et al., 2017), and people with semantic dementia struggle with their language (Volkmer et al., 2019). Therefore, services and attendees at formal dementia services may not be trained sufficiently or are aware of the different symptomatology.

Research to date has mostly investigated the needs of individual subtypes and their family carers. People with Lewy Body Dementia and family carers have specific needs due to the special symptomatology of LBD and its effects on mobility for example, with support needs including information regarding symptomatology and medication, as well as emotional and social support (Galvin et al., 2010; Killen et al., 2016). People with a diagnosis of young-onset dementia are also in a more unique position compared to someone with Alzheimer's disease dementia diagnosed after the age of 65. Due to their young age, many are still in employment or have child care duties. Therefore, a diagnosis brings with it a different situation than an older person with a diagnosis of dementia is likely to be in. These differences are reflected in different wishes for formal dementia care services, as most support groups or activities for example are mostly targeted at older adults and offer more sedentary rather than active pursuits (Giebel et al., 2020b). A systematic review by Millenaar and colleagues (2016) further confirms these findings, as care for people with young-onset dementia was found to be insufficient and not meeting people's needs from the diagnosis through to the post-diagnostic care stages. Cations and colleagues (2017) also found that people with young-onset dementia use formal dementia care services less frequently because services fail to support their needs. Lewy Body dementia and young-onset dementia are not the only rare conditions, and other evidence supports the different needs of various different subtypes (i.e. Johanessen et al., 2017). Importantly, experiencing unmet needs is linked to a lower quality of life (Janssen et al.,

2018), so that identifying suitable care services is vital for rare dementias. However, with these subtypes being cumulatively less common than Alzheimer's dementia, it is worthwhile bringing people with different subtypes and their families together in order to better understand what can be provided for these groups jointly, as providing a community activity only for people with Lewy Body dementia for example would see few people attending merely because of the low numbers of people with a diagnosis in any given community.

The aim of this study was to explore the needs of people with rare dementias and their caregivers, to be supported well in their community. Whilst previous research has looked into the needs of individual subtypes of dementia, this study sought the experiences of dementia care professionals providing services to discuss potential solutions to improve post-diagnostic care for people with rare dementias. Understanding the needs of people with rare dementias can help put into place targeted formal dementia care services, thereby directly addressing one of the priorities of the recently published NHS Long Term Plan (2019).

Methods

Participants and recruitment

Healthcare professionals and dementia care providers were recruited via local care homes, day care centres, memory cafes, as well as through an NHS Trust providing dementia services via posters and by being approached by the respective managers. People with dementia and family carers (18 years or older) of people with any stage and type of dementia, except Alzheimer's disease dementia, were identified through memory clinics at North West Boroughs NHS Foundation Trust, through local carers centres, day care centres, and support groups, and via posters and by being approached by the respective managers.

Staff at the various health care and support settings identified people with dementia and carers as potential participants for the focus groups and approached these with the information sheet. Those that were interested were invited to attend the focus groups. The research team approached dementia care providers and provided them with the information sheet to enquire whether they might be interested in taking part in a focus group.

Ethical approval was obtained from the Health Research Authority and REDACTED before the study (Ref: REDACTED). Written informed consent was obtained at the beginning of the focus groups.

Data collection/ Procedure

Focus groups were held at a local community centre in a town in the North West of England. At the beginning of the focus group, written informed consent was obtained from all participants. Focus groups lasted up to 60 minutes and were audio-recorded and subsequently transcribed.

Focus groups included semi-structured questions about support needs in rare dementias, types of services which could support these needs, how these could be accessed, as well as potential barriers to accessing suitable activities in the community.

Data analysis

Data were analysed using thematic analysis (Braun and Clarke, 2006). Transcripts of the focus groups were coded by two research team members (CG, JC), and codes were subsequently discussed with the public adviser to generate final themes. One research team member (CG) has extensive experience in conducting qualitative dementia research and analysing qualitative data, and provided training to the other team member.

Public involvement

A former family carer of a person with behavioural variant fronto-temporal dementia and motor neurone disease, a very rare dementia condition, helped design the focus group questions, interpret the findings of the focus groups, and helped in the dissemination of the findings both by providing feedback on this manuscript and by being involved in writing a lay summary for the general public. The public adviser was reimbursed for all her contributions according to NIHR INVOLVE (2005) guidelines and had her travel expenses reimbursed.

Results

A total of 18 dementia care professionals participated in this study. Care professionals came from a variety of backgrounds, including clinical psychologists, assistant psychologists, home care workers, care home managers, and home care organisation managers. The majority of professionals were female (89%).

Thematic analysis generated six themes: (1) Complex needs unsupported; (2) Reluctance to approach services; (3) Lack of service adaptation to both people living with dementia and carers; (4) Lack of communication between service providers; (5) Environment of service provision; and (6) Funding issues.

Theme 1: Complex needs unsupported

Professionals highlighted the fact that most services and activities were mostly designed for people with dementia in the early stages of the condition, and with the most common form of dementia, Alzheimer's disease dementia. Staff often only has knowledge of Alzheimer's disease dementia and not of the needs of rarer forms, and how to support people adequately in the more advanced stages with more complex needs. This can often be a substantial barrier for people wanting to attend the services in the first place, as they themselves or their family carers do not feel as if their relative is being adequately supported.

'you're looking at people with rarer types of dementia who then may not be socially acceptable to accept the help from dementia cafes. I personally care for two residents with Korsakoff's dementia and one that also has Lewy Body dementia and they are not socially acceptable to go to cafes, they can't go to days out and bingo nights and things because they can't but where do they get help to find somewhere to meet other people. Because they can't be with people with vascular dementia and things like that because their behaviours are unacceptable to people with different, with different needs'

Focus Group 1

'We did have a gentleman with frontal temporal that was struggling to be in the group and so wasn't able to access so his carer was able to come but he just struggled to be there'

Focus Group 1

'there's a lot of people that are reluctant to go to these groups and not necessarily because they don't want to, but because they can't because of how advanced their dementia is and some dementias where people might be hallucinating or things like that, do we think that there is a gap'

Focus Group 2

This is also reflected in a lack of general trust in the services by unpaid carers, due to the overarching lack of knowledge about specific complex needs of people living with Lewy Body dementia, fronto-temporal dementia, or vascular dementia, for example.

"the carer has to have peace of mind because that is often their loved one or somebody very close to them, so my experience is, you've got to have the trust of the person you're supporting, living with the dementia and also the carer as well, so that they feel confident, that there's no point in them having respite if they're completely not relaxed when they go out."

Focus Group 2

Theme 2: Reluctance to approach services

Service providers pointed out that they encountered many family and unpaid carers who were reluctant to approach services in the first place. This was in some ways due to the fact that they felt they should provide the care to their loved one with dementia, as opposed to handing over care to someone else. This was also considered a generational perception for some, as well as potentially linked with people's socio-economic background. Transport for example was raised as a concern, as public transport can often be limited, and not everyone has access to a car. As a result, some carers only approached service providers when they hit crisis point.

"I think as well is building up that rapport with the carers as well and getting them on board first of all, because they're the ones up caring for these people and we only get them really when they hit crisis and if

we can get in there early on when its first diagnosed then maybe we can put some more support in rather than dealing with something that needs to go into respite"

Focus Group 2

"I think it's also, it's the communities you live in as well. Especially working class areas as well. It's the norm isn't it, you've got an extended family you look after mum and dad."

Focus Group 2

"there's a fear when somebody gets diagnosed that 'oh they might have to go to a day centre, I don't know what a day centre's like'. But if you're already there, doing your talks and things like that and people are going in, they can also see what actually a day centre's like without actually going looking round and so they have an awareness of what's going on and also perhaps maybe if you did it in the residential homes as well, if you had a spare room in there."

Focus Group 2

Participants also highlighted that unpaid carers do not always have someone to look after their loved one with dementia, and are left with no option but to not attend services. This can also be underpinned by financial issues, as carers cannot afford to pay for a paid carer or sitting service coming into the home and support the person living with dementia.

"quite often the carer may not have anybody to support which we all realise is a gap so we were asked if we could actually support the cared for if needed to be to allow the person to attend that course, but again it's how you facilitate that with the skills and everything else but we agreed to it as yet we haven't had anybody that's had to bring the person that they support with them."

Focus Group 1

Theme 3: Lack of service adaptation to both people living with dementia and carers

Some unpaid carers were suggested to feel reluctant in using existing services because they do not offer separate activities for people with dementia and carers. It was felt important to provide services where people with dementia can enjoy a supervised activity, with unpaid carers feeling comfortable and reassured that their loved one is safe and looked after, to then be able to enjoy some time with peers.

"say the men went off to play indoor bowls who might just want to volunteer for the club and so say the men went off to play indoor bowls, say 50/50 split of people with or without dementia so the carers know that they're fine and so if we did an activity for the carers then they'd be quite happy to take part in that 'cause they know that their loved ones are ok"

Focus Group 2

"it's getting people in because they don't necessarily want to come in because like you said before they would have to bring along the mum or dad, the husband or wife."

Focus Group 2

Theme 4: Lack of communication between service providers

Service providers across the focus groups were highlighting the lack of communication across service provider organisations. This led to a lack of knowledge of what types of services might be going on in one postcode area, and result in a duplication of effort. Care staff highlighted that limited funding could be merged instead to ensure that services are delivered to meet the needs of those with rare dementias, without duplicating efforts and wasting limited resources.

"but have a website which is Wigan and Leigh carer's centre. But again we do have the contract with Wigan Council, but one of the things, I've been in post a couple of months is that it's amazing across the patch that we're still unfamiliar with what each other's doing and how we can support each other and sometimes the duplication and it's also when you're accessing funding to provide better services is a joint bid's likely to be more successful and it's like you were saying, which was a brilliant idea"

Focus Group 2

"we access funding differently as well. So again we can cover the cost and fund events and everything which again, it's just working tougher so you support both parties and also as well it's like when you're talking about you get to crisis point and people end up in residential care, if we really support both parties along that pathway, perhaps the need when you get to crisis point you might be able to sort of like take that further down the line."

Focus Group 2

Theme 5: Environment of service provision

Given the complex needs of people living with rarer dementias, care professionals raised the point that going to services outside the home might not be the most suitable form of accessing post-diagnostic support. Instead, people with dementia might be better supported at home in their familiar environment, on a one-on-one basis. This would allow people with dementia to be more supported, particularly if they have complex behavioural or motor functioning needs as is the case with behavioural variant fronto-temporal dementia or Lewy Body dementia.

"I personally think people going into people's homes because that's the environment that they're used to, going out into the community where people are disorientated to time and place it might make them worse, but in their own homes, they may not be familiar with it but they may be, family members might be there as well to support them"

Focus Group 2

“one to one support which I think many people with specifically difficult to understand or support dementias need much more one to one interventions, much more one to one time and it comes down to the old thing of money”

Focus Group 1

“There is no such thing as suitable there is no such thing as one size fits all you could have something that’s entirely suitable for one individual but then the next door neighbour it would not be suitable for them. So it should all be person centred and it should all be on the individual.”

Focus Group 1

Theme 6: Funding issues

This one-on-one support can however be very costly, if it is available in the first place, and people with dementia or carers have to pay themselves if they earn above a certain threshold. This limits the types of services that people can access, even if they are in great need to access support, and results in inequalities in access to care.

“there seems to be a lot available socially for people so if they like singing they like dancing going to group events but we are finding more and more that people who maybe aren’t quite as social who are not comfortable in that environment are just completely left without that option and of course it will be down to funding but often they would be quite happy to fund that themselves if it’s available for them and we do get quite frustrated with the lack of signposting initially after diagnosis.”

Focus Group 1

“She does need the respite all this lady had was half an hour a day just to support him to get washed and dressed, he goes to the day centre twice a week but that’s all her respite. He’s up during the night trying to drag her out of bed because he doesn’t want to be in bed. And she doesn’t know where to go. We are suggesting things for her and it all comes down to funding.”

Focus Group 1

Discussion

This is one of the first studies highlighting the barriers to post-diagnostic service access and utilisation for people with rare dementias and their unpaid carers. While research has identified certain barriers to accessing general post-diagnostic dementia services (Cations et al., 2017), rarer forms of dementia and carers have so far not received a great deal of attention albeit the variations and complex care needs of this population group.

Post-diagnostic care for people with a rare dementia and their unpaid carers appears to be subject to huge barriers in access, ranging from barriers and reluctance of approaching services in the first place to

the feeling that the complex needs of people with for example Lewy Body or vascular dementia are not supported adequately. Whilst barriers were described from the perspective of care professionals, unpaid carers as well as people with dementia had been experienced to have felt unsupported by for example day care centres or peer support groups, as staff is mainly trained in the earlier stages of the most common form of dementia, namely Alzheimer's disease dementia, and most people with dementia and carers attending these social support services being affected by Alzheimer's dementia. Considering the complex needs of for example behavioural-variant fronto-temporal dementia (behavioural difficulties), Parkinson's disease dementia or Lewy Body dementia (motor difficulties), or primary progressive aphasia (vision problems) (Johanessen et al., 2017; Volkmer et al., 2019), it is important that carers feel safe and supported when bringing their loved one with dementia to a day care centre and passing on the responsibility of care to professional staff. This is supported by findings from Wu et al. (2018), who reported that amongst various subtypes of dementia, people with Parkinson's Disease dementia and Lewy Body dementia had the least capability to live well, thus also making recommendations for post-diagnostic services to adapt to the complex need of rarer forms of dementia.

Some suggestions to reduce these barriers for unpaid carers and people with rare dementias include providing specialised training for care professionals to truly understand the complex needs of different rare dementias, and how to best support these in different settings. This might involve care professionals shadowing an unpaid carer for a day, or for those affected by a rare dementia to give a talk and share their experiences. Indeed, a recent systematic review has shown that care focused training around clients' needs was beneficial to older home care clients (Cooper et al., 2017). However, considering that care staff time is generally very limited, with high levels of staff turnover (Costello et al., 2020), these potential solutions might not be feasible and not supported by managers. One other option which would be less time-consuming for care professionals, but in return might also not offer the same benefit, would be for those affected by rare dementias to produce some guidance in terms of what to expect and how to correctly support the various complex needs. Future implementation work needs to address these barriers in order to increase uptake of post-diagnostic support services to ensure that everyone can receive the same level of care.

In addition to more general barriers of perceptions of service users and lack of staff training, funding and transport issues can also cause inequalities in access. A burgeoning evidence base is showing that not everyone affected by dementia receives the same level of support, with access and access greatly dependant on socio-economic factors such as deprivation, ethnicity, education, and geographical living location (Giebel et al., 2020; Morgan et al., 2011; Stevnsborg et al., 2017). In a recent analysis of US data, Giebel and colleagues (2020) for example showed that people with dementia from a minority ethnic background were significantly less likely to use anti-dementia medication. Morgan et al. (2011) reported on barriers to accessing dementia support services by living in more rural regions of Canada, which is signified by reduced and more wide-spread services as well as longer transport time. With most services not being specific to rare dementias, or a specific type of dementia even, and rarer dementias by their very nature being less frequent than Alzheimer's disease, if people want to access a very specific support service, they would potentially have to travel a far distance, which in itself can be stressful and put people

off. Therefore, it is vital that existing social support services are adapted to support the needs of those with rarer dementias, and carers, to enable more opportunities for receiving the care they need.

This study is subject to some limitations though. This is an exploratory study which is primarily based on the experiences and perceptions of care professionals. This is because it proved very difficult to recruit people living with rare dementias and family carers in the region, whilst care professionals from all different care backgrounds (including managers, care homes workers, day care centres, psychologists, and support workers) took part and therefore provided a broad range of expertise and experience. Future research needs to capture the experiences of those affected by rare dementias more targetedly, which may be better facilitated in more private interview settings also. Furthermore, findings from this study are based on one region within England only, and may not be representative of the wider country. However, this is an exploratory study into this still under-researched subject area, which also benefits from a broad range of clinical and non-clinical professional expertise.

Conclusions

People living with a rare form of dementia and their carers are facing significant barriers to accessing and utilising post-diagnostic support that can help them stay live well for longer. This appears to be one of the first studies to have explored the issues of post-diagnostic care uptake in all forms of rare dementia, and clearly highlights the need for the adaptation and training delivery in existing social support services, such as day care centres, to support those complex needs. Considering large inequalities in dementia care already (Stevnsborg et al., 2017), it appears that being affected by a rare form of dementia creates an additional layer of unequal post-diagnostic support access, so that future implementation work needs to specifically focus on making existing services more user friendly.

Declarations

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Competing interests

The authors declare that there is no conflict of interest.

Ethical approval

Ethical approval was obtained from the Health Research Authority and the Haydock North West Ethics Committee before the study (Ref: 19/NW/0344). Written informed consent was obtained at the beginning of the focus groups. This research was performed in accordance with the Declaration of Helsinki.

Data availability

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Authors' contributions

CG, JC, and AP applied for funds and conceptualised the grant application. CG, JC, SS, and AP conceptualised and developed the full project and co-produced topic guides. CG applied for ethical approval, collected data, led on the analysis and write up of the study and paper, and managed the overall project. JC collected data and contributed to the analysis. All authors have read and approved the manuscript.

Consent for publication

Not applicable.

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