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1136 Remote Consultations for People with Parkinson's and Cognitive Impairment – A Qualitative Study

JS Pigott¹, M Armstrong², E Chesterman¹, J Read¹, D Nimmons², K Walters², N Davies², A Schrag¹

1. Queen Square Institute of Neurology, University College London, London, United Kingdom; 2. Centre for Ageing Population Studies, Research Department of Primary Care and Population Health, University College London, London, United Kingdom

Background

The Covid-19 pandemic led to many consultations being conducted remotely. Cognitive impairment is recognised as a potential barrier to remote healthcare interactions and is common but heterogeneous in Parkinson's. Little is known about these consultations in real life. We explored the experiences of remote consultations for people with Parkinson's and cognitive impairment, investigating the perspectives of people with Parkinson's, caregivers and healthcare professionals.

Method

Semi-structured interviews were conducted remotely (video or telephone) with 11 people with Parkinson's and cognitive impairment, 10 family caregivers and 24 Healthcare Professionals in 2020-2021, using purposive sampling. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

Results

Four themes were identified: (1) The Nature of Remote Interactions; (2) Challenges Exacerbated by Being Remote; (3) Expectation versus Reality; and (4) Optimising for the Future. Remote consultations were considered 'transactional' and less personal, with difficulties building rapport, and perceived to have a different role to in-person consultations. The loss of non-verbal communication and ability of Healthcare Professionals to 'sense' led to remote consultations being perceived as riskier by all groups. Specific to this population, issues arise from both communication and cognitive impairment; balancing of the person with Parkinson's and caregiver voice; and around significant discussions, for example, regarding the future. Remote consultations were reported to have been more successful than anticipated in all three groups. Obstacles were not always as expected, for example age was less of a barrier than anticipated. Potential improvements for these three groups and healthcare services were identified, for example, consideration of camera positioning for video calls; and service flexibility to allow consultations to be timed to optimal medication function.

Conclusion

Advantages and challenges of remote consultations for this population are identified. Consultations could be improved with increased support, practice, preparation, awareness of issues, and more time and flexibility within services.

Remote Consultations for People with Parkinson's and Cognitive Impairment: A Qualitative Study with Patients, Caregivers and Healthcare Professionals

JS Pigott, M Armstrong, E Chesterman, J Read, D Nimmons, K Walters, N Davies, A Schrag - University College London

BACKGROUND

- The Covid-19 pandemic led to many consultations being conducted remotely
- Cognitive impairment is a recognised barrier to remote consultations
- Cognitive impairment is common but heterogeneous in Parkinson's

AIM To explore the experiences of remote consultations for people with Parkinson's and cognitive impairment, investigating the perspectives of people with Parkinson's, caregivers and healthcare professionals

METHODS

- Qualitative study using semi-structured interviews, conducted remotely in 2020-2021.
- 11 people with Parkinson's and cognitive impairment, 10 family caregivers and 24 Healthcare Professionals participated.
- Data analysed using reflexive thematic analysis.
- Multidisciplinary and Patient & Public Involvement throughout.

FINDINGS

Sample Quotes

"I don't always feel that there is a proper dialogue. It's a question-and-answer sort of thing that goes on. But it sounds a bit mechanical. Sort a list of things to tick off" Person with Parkinson's

"I hate using the phone. I get on the phone and then I don't understand people" Person with Parkinson's

"I thought I would be quicker" Neurologist

"I did my research, I interviewed my mother beforehand, found out how she was feeling therefore what I wanted to know. So, I was ready for the call." Caregiver

Themes & Subthemes

1. The Nature of Remote Interactions

- (a) A Transactional Exchange
- (b) Is it "Real"?
- (c) A Risky Process

2. Challenges Exacerbated by Being Remote

- (a) Communication & Understanding
- (b) Interpersonal Dynamics
- (c) Significant Discussions

3. Expectation Vs Reality

- (a) Anticipated Barriers
- (b) Expected Advantages

4. Optimising for the Future

- (a) Support for People with Parkinson's & Caregivers
- (b) Professional Development
- (c) Service Improvement

CONCLUSIONS

Lessons for Future Consultations



- Practice
- Preparation – Environment; Issues to discuss
- Timing – e.g. medication effectiveness



- Awareness of how it is received
- Avoid excluding person with Parkinson's
- Allow time, don't cut in
- Explain and reassure



- Provide guidance, not just written instructions
- Flexible services
- Simple platforms
- Build in time & frequency

CQ - Clinical Quality - CQ - Clinical Effectiveness**1166 Co-existing essential tremor and Parkinson's disease - experiences of a movement disorder service**

L Evans, F Collier, L Ebenezer, S Raha

Princess of Wales Hospital Movement Disorder Service, Bridgend, Cwm Taf Morgannwg University Health Board

Introduction

Essential tremor (ET) and Parkinson's Disease (PD) are common causes of tremor. Movement disorder service (MDS) involvement is often required to distinguish these conditions and they may co-exist. Compared to ET and PD there is a paucity of data on the combination of essential tremor with Parkinson's Disease (ET-PD). We have evaluated our MDS to compare up-to-date experience with existing data and to identify areas for further study.

Methods

We filtered 3244 patient records on our MDS clinical database for "essential tremor" and "Parkinson's Disease". Data was collected, analysed and comparisons made to an n=53 ET-PD group described by Minen & Louis, 2008.

Results

ET was diagnosis in 798. There was both ET and PD in 13; 1.6% of all ET. In ET-PD mean age at PD diagnosis was 75 years, range 60-87 (cf. 66 years, range 35-87, Minen & Louis, 2008), 7 (54%) were female (cf. 32%). There were dual diagnoses at presentation in 3 (23%), 10 (77%) had established ET and later developed PD. In pre-existing ET, the median time until PD diagnosis is 34 months, range 6-258 (cf. 86 months, range 7-656). DAT scans were performed in 9 ET-PD; all were abnormal, 6 showed bilateral striatal involvement and 7 showed increased background activity.

Conclusions

There is an increased risk of those with ET developing PD, even in a MDS, however our data suggests absolute risk is low. In the majority of cases a diagnosis of ET is made and then PD develops later, the latency of onset of PD in our data is shorter than that previously described. We have identified a group that have ET-PD at onset not described in the previous study. We have shown that increased background activity and bilateral involvement on DAT scan is common in ET-PD. Further research can explore this.

Co-existing essential tremor and Parkinson's disease

Experiences of a movement disorder service

L Evans, F Collier, L Ebenezer, S Raha
Princess of Wales Hospital Movement Disorder Service
Cwm Taf Morgannwg University Health Board

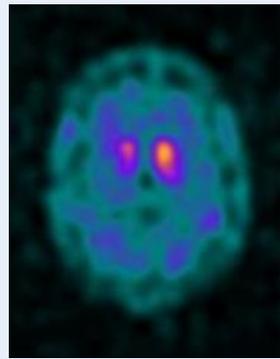
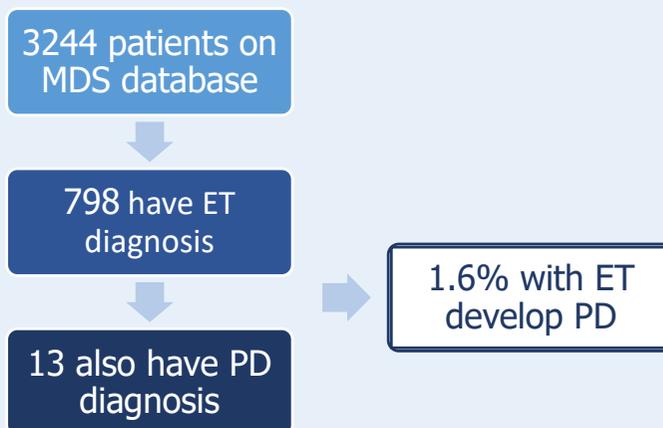


Figure 1.
DAT scan showing bilateral reduction in striatal uptake and increased background activity in a patient with ET-PD

We evaluated our South Wales based movement disorder service (MDS) to compare up-to-date experience with existing data on the combination of essential tremor with Parkinson's Disease (ET-PD). Our MDS clinical database records were filtered for "essential tremor" and "Parkinson's Disease". Comparisons of the data collected were made to an n=53 ET-PD group described by Minen & Louis, 2008.

Figure 2.
Flowchart



There were dual diagnoses at presentation in 3 (23%) whilst 10 (77%) had established ET and later developed PD.

Figure 3.
Table comparing our MDS to existing data

	MDS data	Minen & Louis 2008
Age (years)	75 (60-87)	66 (35-87)
Female (%)	54	32
Median ET to PD latency (months)	34 (6-258)	86 (7-656)

In our movement disorder service...

- Absolute risk of patients with ET developing PD is low; 1.6%
- Median time from ET to PD diagnosis is around 3 years
- We describe a group with dual diagnosis at presentation

Reference

Minen MT, Louis ED. Emergence of Parkinson's disease in essential tremor: a study of the clinical correlates in 53 patients. *Mov Disord.* 2008 Aug 15;23(11):1602-5

CQ - Clinical Quality - CQ - Improved Access to Service []

1167 Improving understanding of Lewy body dementia and supporting familie ; the role of the Admiral Nurse

AMLove; RThompson

Dementia UK

Introduction

Lewy body dementia (LBD) is the second most common cause of neurodegenerative dementia and includes two related disorders, dementia with Lewy bodies (DLB), and Parkinson's disease dementia (PDD). It is a complex and challenging condition accounting for 10-15% of dementias; affecting approximately 100,000 people in the UK (Stevens et al 2002). However compared with other dementias, LBD is often misdiagnosed and misunderstood (Kane et al 2018). People with LBD and their family carers often experience poor mental and physical health, reduced quality of life and high levels of strain/burden (Wu et al 2018, Vatter el al 2020, Bentley 2022).

Method

During 2020 - 2021 a Consultant Admiral Nurse post for Lewy body dementia was introduced by Dementia UK and the Lewy Body Society. The aims were to provide professional leadership & consultancy, education & training and expert clinical practice to families, nationally. A service evaluation gathered information about referrals, numbers of families, clinical interventions and supporting best practice activities. Carers and people living with Lewy body dementia were surveyed about their experiences of the service, including the difference it made. Training on LBD was delivered to 168 Admiral Nurses and a pre- and post-training tool used to evidence change in knowledge and approach to care.

Results

Over a 12 month period the service provided a range of interventions including psychoeducation and emotional support, via phone or video, to 71 carers and people with LBD. Survey feedback from 35 people indicated a positive experience of the service and support led to an increase in understanding and ability to manage symptoms plus improvements in coping.

Conclusion(s).

The evaluation demonstrated the service was well received and made a positive impact on those who received support. Future developments include evaluating further the impact of clinical support and development of training for other professionals.

Improving support and understanding of Lewy body dementia

Evaluation of a Consultant Admiral Nurse service 2020-21

Admiral Nurses are specialist dementia nurses who provide psychological support, advice and information to help families affected by dementia. People with Lewy body dementia account for 10-15% of all dementias and experience complex physical and psychological needs. Those caring for them often have high levels of stress and depression. In 2019 the Lewy Body Society funded a two-year project for a Consultant Admiral Nurse specialising in Lewy body dementia, in partnership with Dementia UK.

Aim

The aim of the project was to provide leadership and consultancy, education and training, and expert clinical practice nationally, through:

- raising awareness of Lewy body dementia
- increasing understanding of the needs of families affected by Lewy body dementia
- offering direct support for families with complex needs

Methodology

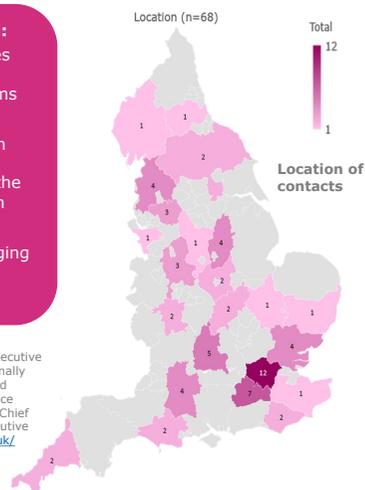
A 'mixed methods' approach was used, collecting qualitative and quantitative data:

- Activities were captured on a clinical database
- Family carers and people living with dementia were asked to take part in a survey about their experience of the service, including the **CARE (Consultation and Relational Empathy) measure**¹
- Professionals taking part in training (n=168) were asked to complete a bespoke pre- and post-training tool to measure changes in knowledge and approach to care

Referrals to the service

Reasons for referral:

- significant difficulties with managing distressing symptoms (38%)
- significant distress in relation to caring/adjusting to the diagnosis/changes in relationship (31%)
- difficulty with managing medication; co-morbidities (12%)



1. © CARE: SW Mercer, Scottish Executive 2004. The CARE measure was originally developed by Dr Stewart Mercer and colleagues as part of a Health Service Research Fellowship funded by the Chief Scientist Office of the Scottish Executive (2000-2003): caremeasure.str.ac.uk/

Outcomes

Survey responses were received from 30 carers and five people with dementia. No question in the survey was mandatory therefore response rates to questions varied.

Carers said the Admiral Nurse had contributed to:

- their ability to continue as a carer (28 out of 30)
- avoiding a care or nursing home move (10 out of 30)
- reducing GP appointments for their own needs (10 out of 30)
- reducing GP appointments for the person with dementia (9 out of 30)
- avoiding A&E visits for the person with dementia (8 out of 30)

All or almost all carers and people living with Lewy body dementia said the Admiral Nurse had made a difference to:

My ability to cope (34 out of 34)

My understanding of Lewy body dementia (34 out of 34)

My knowledge of other services that can support (33 out of 33)

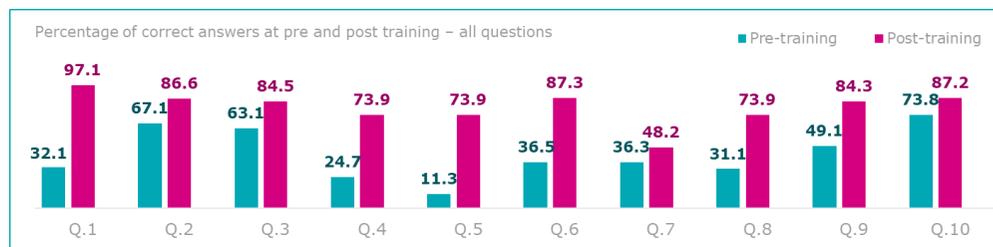
My ability to manage symptoms (30 out of 31)



Training delivered had a positive impact on Admiral Nurses' knowledge about Lewy body dementia and their approach to care

A bespoke multiple-choice questionnaire was developed and tested internally – designed to measure changes in knowledge and approach to care.

The percentage of correct answers across all questions increased from pre- to post-training.²



2. 168 questionnaires were completed pre-training and 142 post-training. The percentage of correct answers from pre- to post- across all of the questions increased from 11.9% to 65%. When interpreting the percentage increase in correct scores, consideration should be given to the different number of pre- and post- questionnaires completed.

Delivering support

71 family carers and people living with Lewy body dementia were directly supported following a referral.

The service delivered support to families mostly by telephone, video call and email.



620 activities supporting families



Families' needs were assessed to ensure person-centred care and support was provided by the service, as follows:

- help with developing coping skills and strategies
- enhancing knowledge and understanding of Lewy body dementia
- emotional support and counselling, including adjusting to bereavement and loss

Summary:

- 87 referrals to the service
- 71 family carers and people living with dementia supported
- 620 clinical interventions delivered
- 164 supporting best practice activities delivered – including training to 168 Admiral Nurses
- 73 liaison activities with professionals



The Lewy Body Society
Shining a light on Lewy body dementia