

SIALORRHEA SURVEY REPORT

Data collection to help understand the
impact of sialorrhea and build awareness of
therapy options for people with Parkinson's



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THERAPEUTICS



Merz Therapeutics were involved in the design and data analysis of the original patient survey and reviewed the final report for factual accuracy, but the responsibility for the conclusions of the survey lies with the EPDA



The voice for Parkinson's in Europe

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INTRODUCTION



Drooling, also known as sialorrhea, may seem like a relatively minor symptom of Parkinson’s, but it can have a huge impact on the quality of life of those who are affected by it. In September 2020, the European Parkinson’s

Disease Association (EPDA) began a new data collection project to understand the burden that drooling represents – from a physical, wellbeing and daily living perspective – for people living with the condition. We wanted to gather information about if, when and how this symptom is addressed by healthcare professional teams.

The interesting and important findings presented in this report will help us raise

much-needed awareness about the prevalence of sialorrhea, as well as the treatments available.

The EPDA is constantly working to help people with Parkinson’s receive the right information at the right time, as well as early and appropriate treatment and individualised care. It is incredibly important to raise awareness about the impact of lesser-known symptoms such as sialorrhea, to ensure they are appropriately addressed by healthcare professionals. If we all work together to achieve this, improvements in the quality of life – for people with Parkinson’s, their families and carers – can become a reality.

Russell Patten, Director General of the EPDA

PARTNERSHIP

This data collection project was made possible with the financial support of our partner Merz Therapeutics, a business unit of Merz Pharmaceuticals GmbH.

The survey results and individual data are the property of the EPDA.



The voice for Parkinson’s in Europe

EXECUTIVE SUMMARY: SIALORRHEA – AN OFTEN- OVERLOOKED PROBLEM IN PEOPLE WITH PARKINSON’S DISEASE



Apart from the classical motor symptoms of Parkinson’s – such as tremor, rigidity and bradykinesia (slowing of movements) – in recent years non-motor symptoms are increasingly being

recognised as part of the disease.

For instance, sialorrhea or drooling – the unwanted loss of saliva – is a symptom that can be particularly troublesome to many people with Parkinson’s (PwPs). Many factors are thought to contribute to sialorrhea in the condition: an increased production of saliva; the stooped (bent-forward) posture in many PwPs; and a decreased swallowing frequency.

Sialorrhea can be very undesirable. It can result in PwPs reducing their social contacts – which will hopefully normalise after the current Covid-19 pandemic – out of embarrassment. Its often-unexpected occurrence only aggravates the problem.

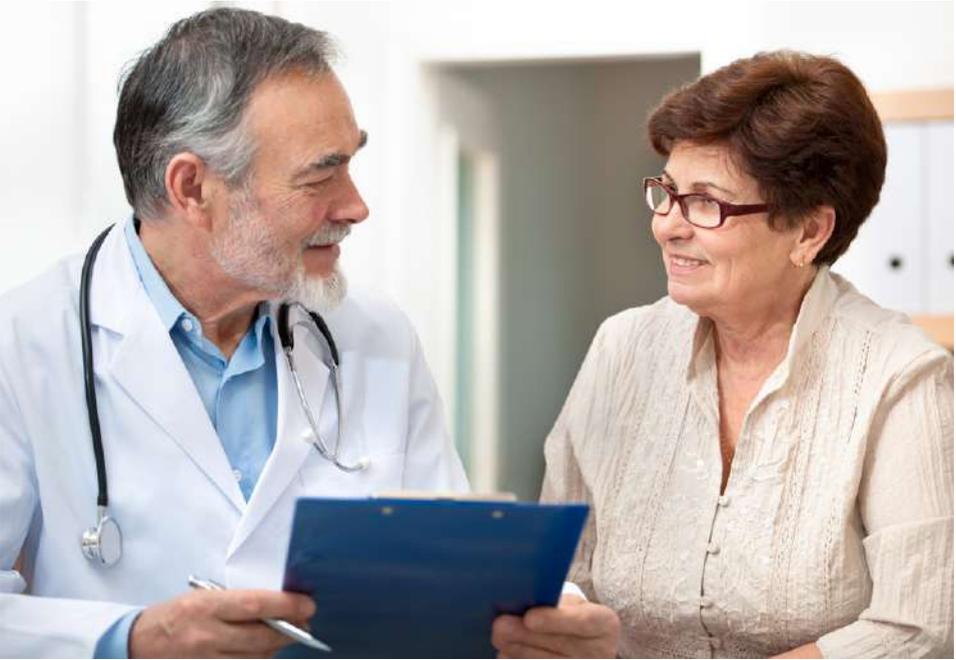
Recent evidence suggests sialorrhea is more prevalent than previously thought. In a recent European Parkinson’s Disease Association (EPDA) survey (whose results are detailed in this report), 67% of respondents said they

had it. The majority of PwPs in this survey said they had moderate to severe sialorrhea (meaning it was also present during the daytime and/or required tissues). Sialorrhea was present “frequently” to “constantly” in more than 50% of respondents. Most PwPs recognised the link between their sialorrhea and Parkinson’s. Surprisingly, however, almost half of the respondents (45%) had not (yet) talked about this concern with any of the healthcare professionals that take care of them. Only one quarter (27%) of respondents that suffered from this symptom had received a medical diagnosis of sialorrhea.

‘Social embarrassment is the number-one key issue that people with Parkinson’s experience’

Sialorrhea can be troublesome for many reasons. Social embarrassment is the number-one key issue that PwPs experience. The negative effect of sialorrhea can be wide-ranging, with PwPs mentioning how it impacts their speech, eating and swallowing. For many people and their carers, sialorrhea causes physical discomfort, whereas skin irritation is negligible.

The main negative impact PwPs experience is on their self-esteem, which can increase feelings of anxiety and depression. Sialorrhea has a big impact on people’s social lives and can often lead to increased isolation. The psychological burden of neurodegenerative diseases on patients and carers is already severe. Sialorrhea can contribute to this burden.



Despite the impact of sialorrhea on PwPs' wellbeing, this recent EPDA survey suggests this symptom is often neglected. Accordingly, less than half of respondents have ever been recommended any therapy. When they have, speech and language therapy, followed by simple swallow reminders or other drugs/medication/aids such as chewing gum, were the most common. These limited choices can lead to people wrongly thinking no treatment options are available.

As a neurologist specialising in movement disorders, I would like to give you one piece of advice: if you experience sialorrhea or any other symptoms that you feel could be linked to your Parkinson's, don't be afraid to talk about it with your neurologist and/or healthcare professional team.

‘Don’t be afraid to talk about your Parkinson’s symptoms with your neurologist and/or healthcare professional team’

They will be able to tell you whether there is a link with Parkinson's and propose any treatment options that may be available.

Dr Bruno Bergmans, MD, PhD

Neurologist specialising in movement disorders at AZ St-Jan Brugge and Academic consultant Ghent University Hospital

Merz Therapeutics, a business unit of Merz Pharmaceuticals GmbH, has provided financial sponsorship to the author for the development of this article but has had no input into the content of the article.

METHODOLOGY

Survey

Versions of this online, self-completed questionnaire were provided in English, German, French and Spanish. Responses were received between 14 October 2020 and 30 November 2020.

Countries covered

Key countries: Germany, Spain, France, US, Canada, UK (N=331)

Further countries: Argentina, Australia, Austria, Bahrain, Cuba, Finland, Greece, Ireland, Israel, Italy, Luxembourg, Malta, Mexico, Netherlands, New Zealand, Norway, South Africa, Switzerland, Turkey, Venezuela (N=44; 7 NA)

Sample size

- gross: N=569 (that clicked on the survey link)
- net: N=382 (67% that carried on and qualified themselves as having sialorrhea)



METHODOLOGY

Net response and language distribution

A total of **382 respondents** qualified as a person with Parkinson's or a carer of a person with Parkinson's (67% of the 569 that actually started the survey)

By language

English 237 (62%)

French 61 (16%)

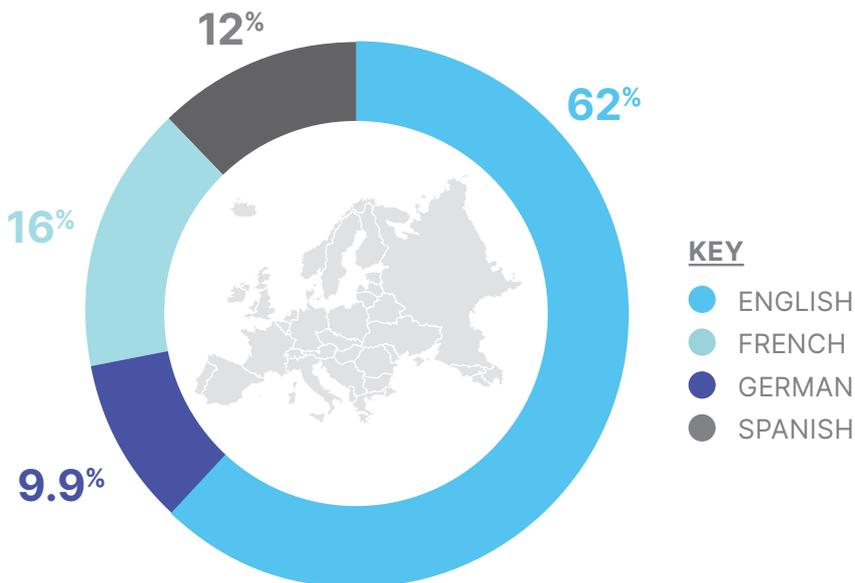
German 38 (9.9%)

Spanish 46 (12%)

Total: 382 (100%)



Language distribution

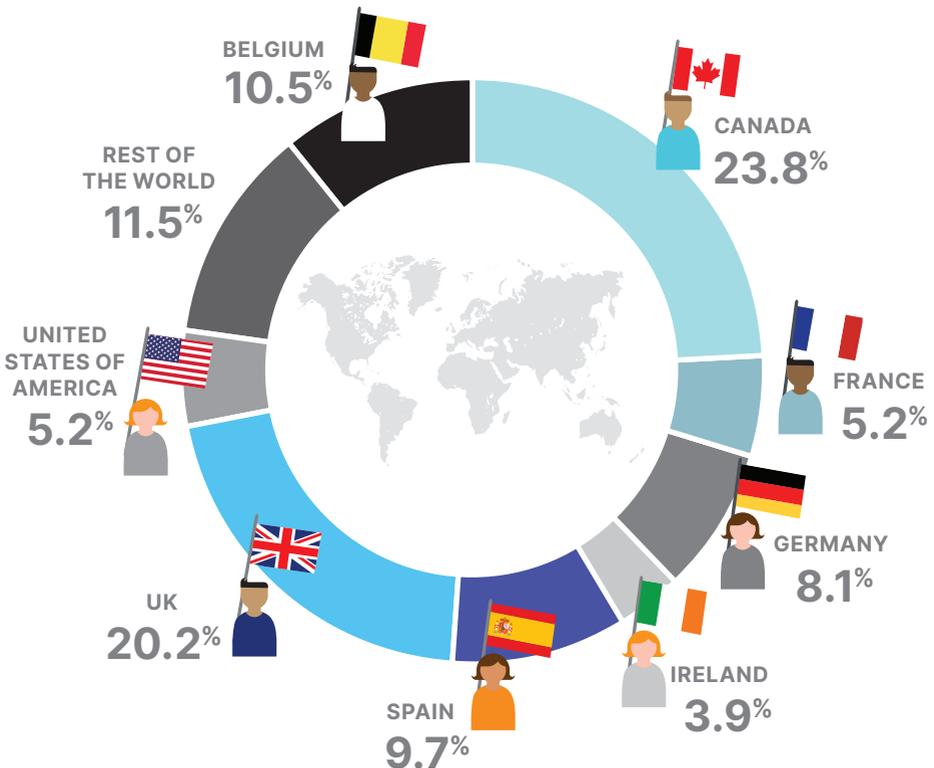


METHODOLOGY

Respondents answered the questionnaire from all over the world – a diverse sample

- **Nearly one quarter** of responses come from **Canadian people with Parkinson's**
- Another **20%** are from the **UK**
- **Spain** provided nearly **10%**, **Germany 8%** and the **US 5%** of responses
- The French speaking respondents are mainly from **Belgium** (10.5% of total respondents) **and France** (5%)
- Responses from the “**rest of the world**” came from Malta, Australia, Switzerland, the Netherlands, Finland, Italy, Greece and Israel – but also from beyond Europe, including Mexico, Argentina and Venezuela

Where respondents came from



KEY HIGHLIGHTS



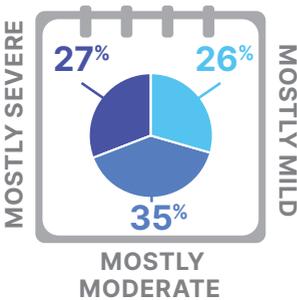
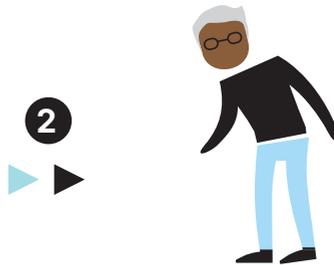
KEY HIGHLIGHTS

Summary/key results



1 **382 people** from all over the world – **the majority of which have Parkinson's** and experience drooling – took part in the survey.

The majority were between **60 and 80 years old** and more men than women responded.



3 Respondents' self-assessment of their condition was **"mostly mild"** (26%; some drooling during sleep only), **"mostly moderate"** (35%; some drooling also when awake, but usually no tissues needed), or **"mostly severe"** (27%; regularly need tissues/handkerchiefs).

There is a **high awareness** amongst respondents (86%) that drooling is a potential side effect of Parkinson's – **only 14%** state that they are unaware of this fact.



KEY HIGHLIGHTS

► Summary/key results

Less than half of respondents have discussed sialorrhea with their healthcare professional or specialist who cares for them. Even less have yet received an official diagnosis of sialorrhea (only 27%).



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Besides physical problems, such as difficulties with swallowing, experiencing a dry mouth or skin irritation, the main impact **drooling** has on respondents' lives is of a **social and strong emotional nature**: approximately **40%** claim that **social embarrassment** is the one key issue they struggle with in their daily lives. The second main issue – the impact on **speech and communication** – is reported by roughly **20%**.

For most respondents, **drooling is worse during the night/when sleeping**. Some wake in the night, while other wake in the morning to wet pillowcases that need frequent changing. Others find they suffer most before bedtime, in the evening.



A number of respondents report feeling highly embarrassed, even angry, about not having one's body under control, of being stared at. Respondents are very aware of the mess it makes – staining pillowcases and clothes – as well as how unhygienic it is, especially given the heightened awareness brought about by the Covid-19 pandemic. They worry about wearing a wet mask, or “spitting” at people they're talking to by accident. Speech is disturbed, as well as swallowing. And at night, when drooling is worse for most people, sleep is disturbed too (people wake up). These factors combined can lead to less social interaction and even total withdrawal, which again may reinforce depressive tendencies.



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KEY HIGHLIGHTS

► Summary/key results

The main contact for respondents is the **neurologist**, followed by the **family doctor/ GP**. To some extent, **physiotherapists** – as well as speech and language therapists, and in the UK, the Parkinson's Nurse Specialist (PDNS) – are involved with their care.



According to respondents, these **healthcare professionals (HCPs) do not pay much attention** to the impact drooling has on their social/daily life. They feel, rather, that it is a quite strongly neglected aspect of their condition.

Less than half of respondents have ever been recommended any therapy. Those that have most often undergo speech and language therapy.



Simple **swallow reminders** and other drugs/medication are the next-most-tried therapies, with roughly 6% having tried injections. Chewing gum and sucking on sweets have also been suggested.

In general, patients are **moderately satisfied** with the result of these therapies – **however, there is room for improvement.**



RESULTS OF SURVEY

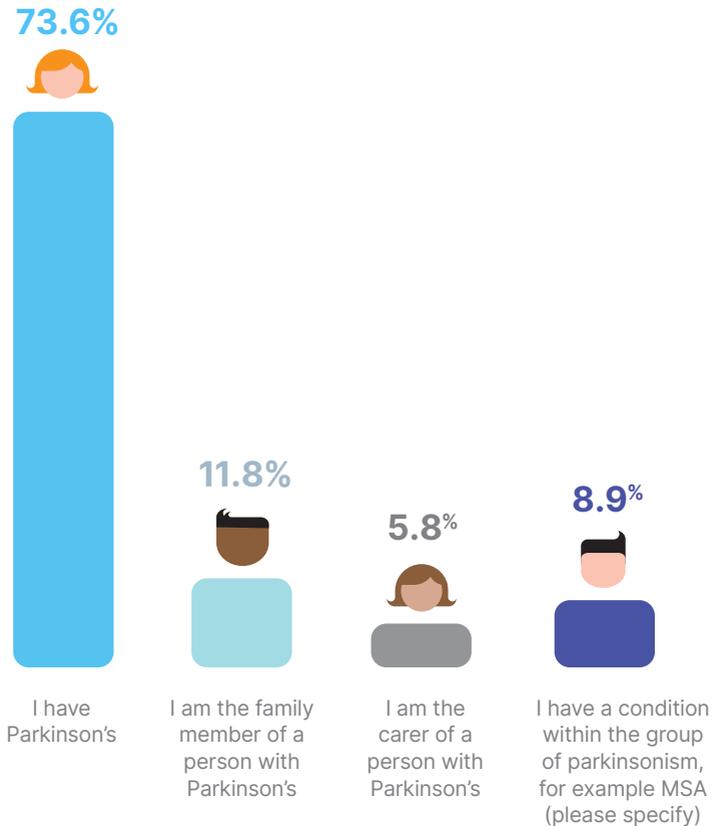


RESULTS

► **The majority of respondents are people with Parkinson's or carers of people with Parkinson's**

- About **three quarters** of the respondents have Parkinson's themselves
- Nearly **20%** of the respondents are either a **family member** or the **carer of somebody with Parkinson's**
- Roughly **9%** do not have Parkinson's directly, but have another condition such as Multiple System Atrophy (MSA)*

Relationship with Parkinson's



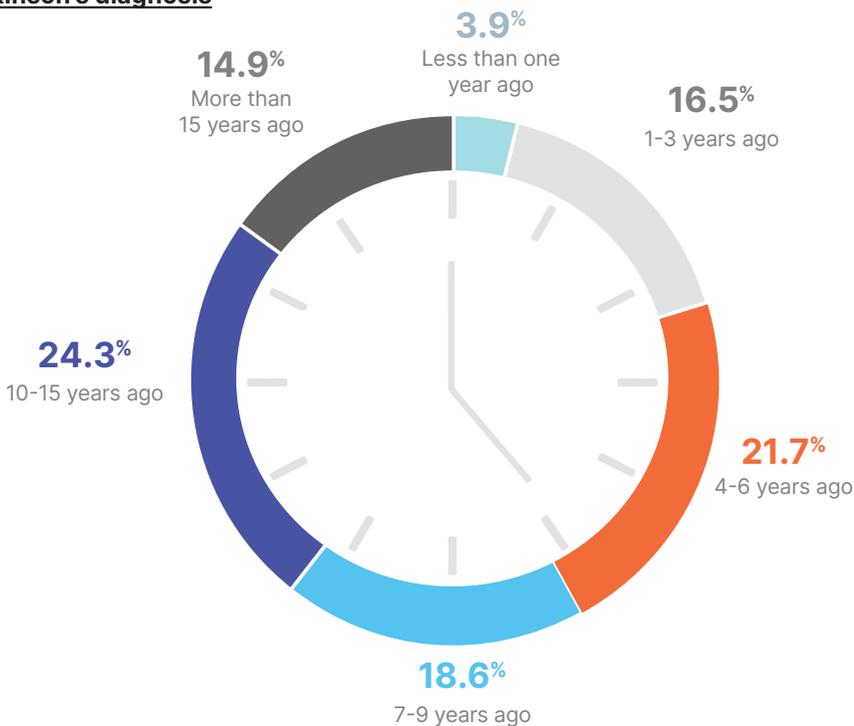
*Survey was opened to people with MSA after publication of the online questionnaire

RESULTS

► Time since Parkinson's diagnosis



Parkinson's diagnosis



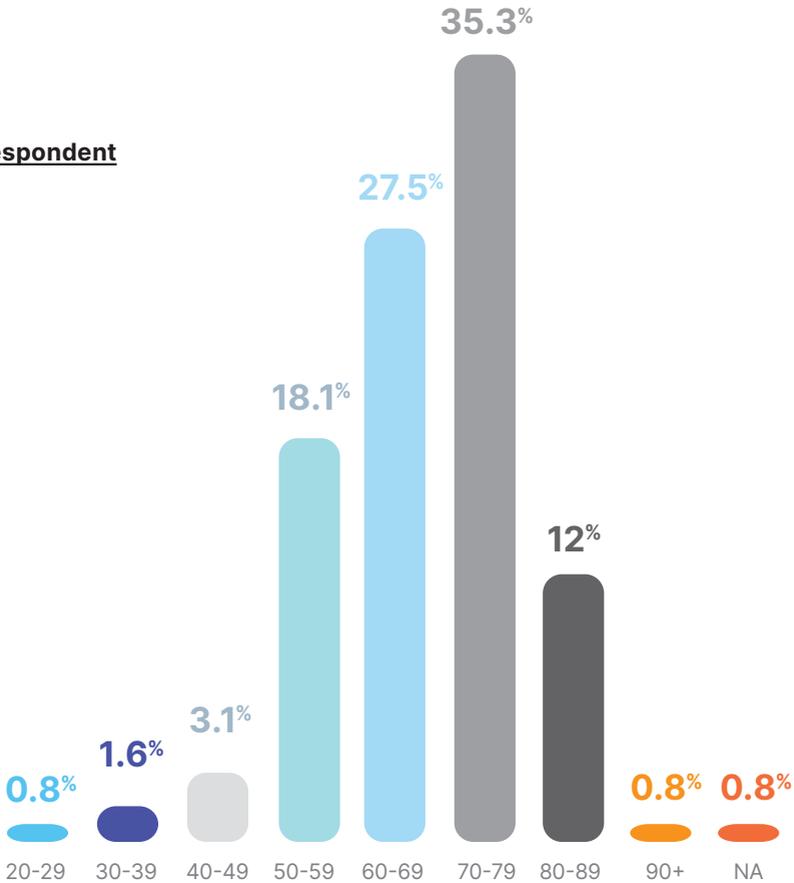
Question 5: When were you/your family member/the person you care for diagnosed with Parkinson's?

RESULTS

► Age – majority 60 to 80 years old

- **Most** respondents are at least **50 years old**
- The **majority of these are 70-79 years old**, followed by the 60-69 years old
- **12%** of respondents are **over 80 years old**

Age of respondent

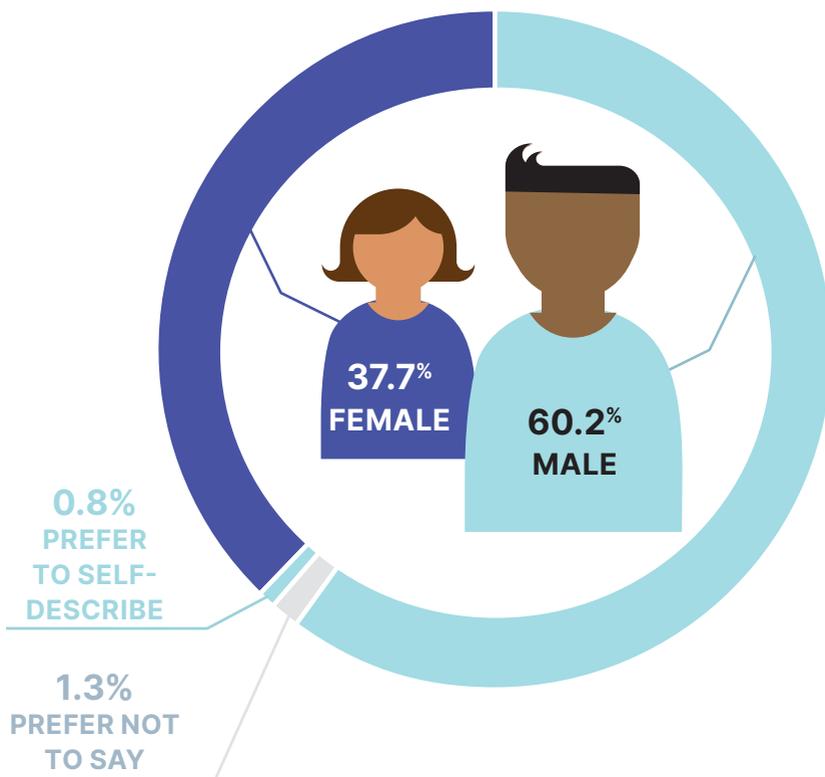


Question 6: How old are you/your family member/the person you care for?

RESULTS

► Gender – more males

Gender

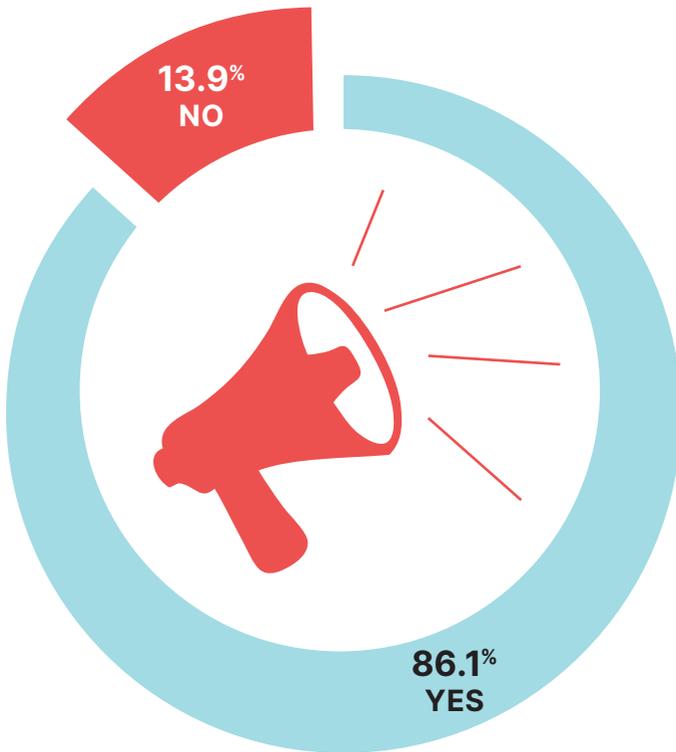


Question 7: What is your gender?

RESULTS

► **High awareness of sialorrhea as a symptom of Parkinson's**

Awareness of sialorrhea as a Parkinson's symptom

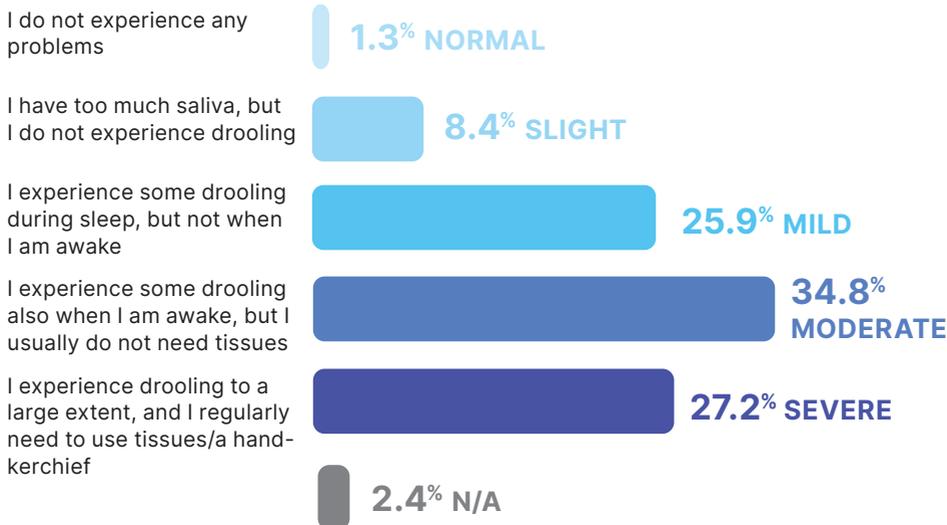


Question 8: Do you know that drooling (sialorrhea) can be a potential symptom of (underlying) Parkinson's?

RESULTS

► Severity and frequency

Severity of drooling (self assessment)

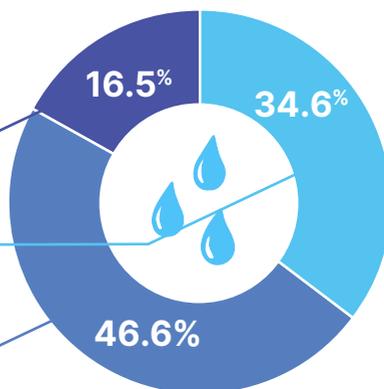


Frequency of drooling

CONSTANTLY

OCCASIONALLY

FREQUENTLY



Question 10: How severe would you say this drooling is?

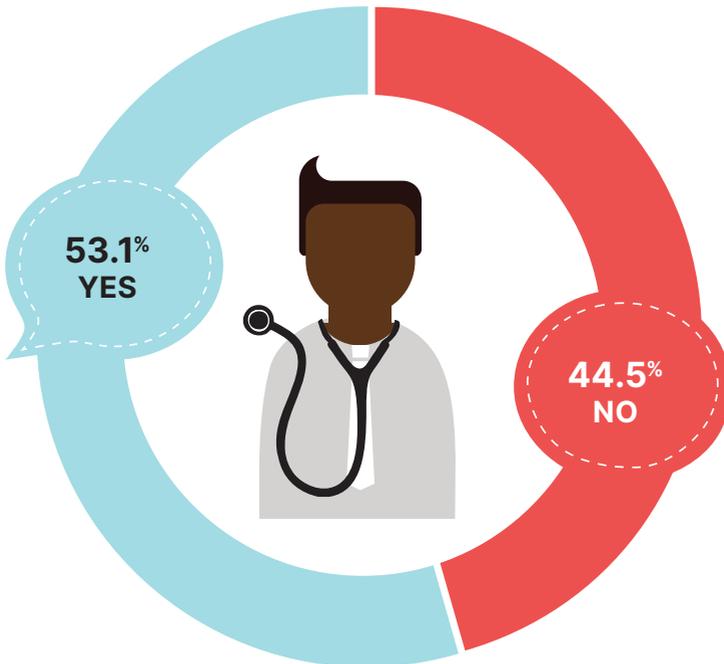
Question 11: And how often do you/your family member/the person you care for experience drooling?

RESULTS

► **Sialorrhea – not always a topic of discussion with medical team**

- **Slightly more than half** of the respondents have discussed the topic of drooling with a healthcare professional
- **45% have not** (yet) talked about drooling with any of the healthcare professionals that take care of them

Talked with care/medical team



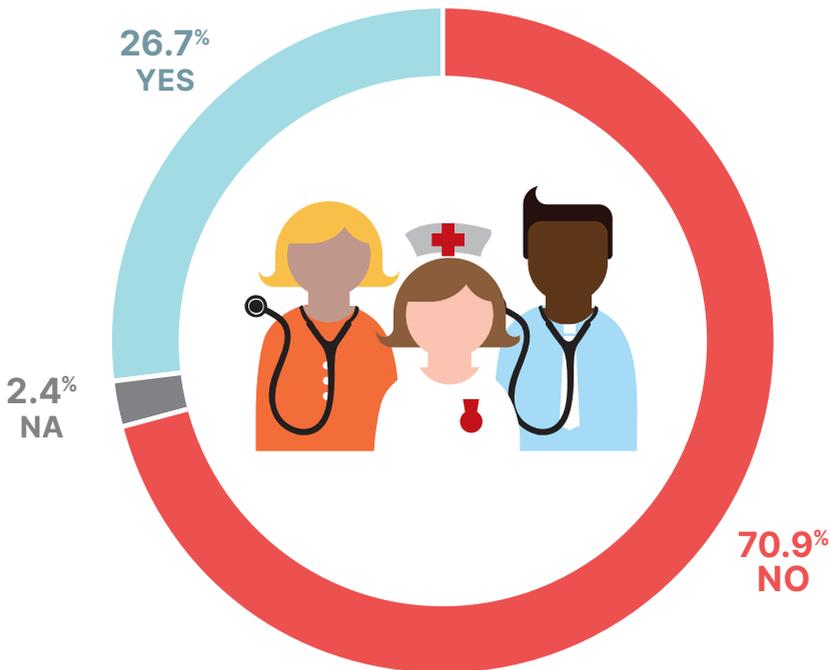
Question 8: Have you/your family member/the person you care for discussed this symptom with any member of the healthcare team involved in your care?

RESULTS

► Official diagnosis of sialorrhea

- **Only one quarter** (27%) of patients that suffer from sialorrhea have received an official medical diagnosis
- **71% have not** received an official diagnosis of sialorrhea

Received official diagnosis



Question 13: Have you/your family member/the person you care for received an official diagnosis of drooling (sialorrhea) from any of the healthcare professionals involved in your multidisciplinary care team?

RESULTS

► **Key issues about sialorrhea (open-ended question)**



*** Responses by English-speaking respondents**

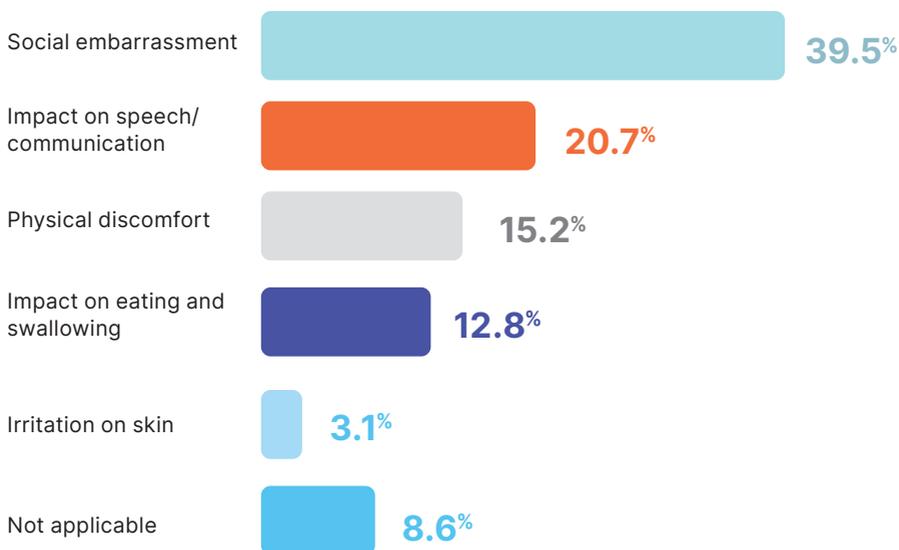
Question 14: What are the key issues about drooling that bother you/your family member/the person you care for the most?

RESULTS

► Social embarrassment the main problem for people experiencing sialorrhea

- Social embarrassment is the number-one issue that respondents suffer from – **reported by roughly 40%**
- Another **20% stated sialorrhea impacts their speech**
- **15%** experience **physical discomfort**
- Approximately **13%** say there is an impact on **eating/swallowing**
- For 3%, **irritation of the skin** is the key issue

Key issue (single choice)



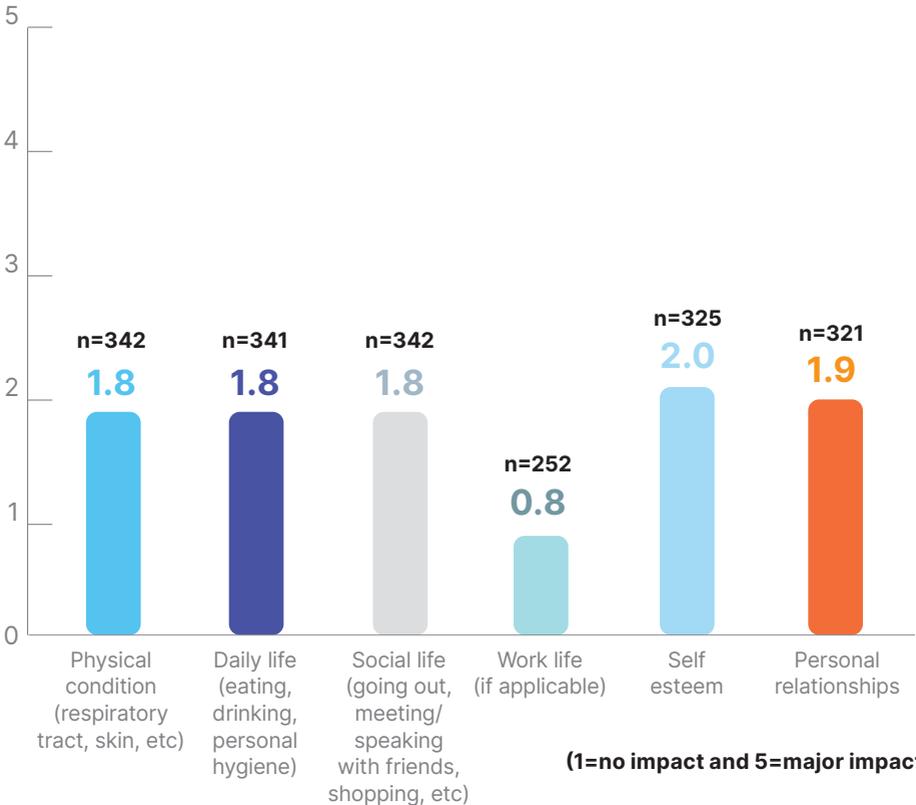
Question 15: Which of the following key issues about drooling would you say bothers you the most? (please pick one)

RESULTS

▶ Most severe impact is on self esteem and personal relationships

- Respondents report that drooling mainly impacts their **self esteem**, followed by personal relationships
- The impact sialorrhea has on **respondents' daily and social lives** is as severe as the impact of the physical symptoms (on the respiratory tract, skin irritation)

Impact on daily life

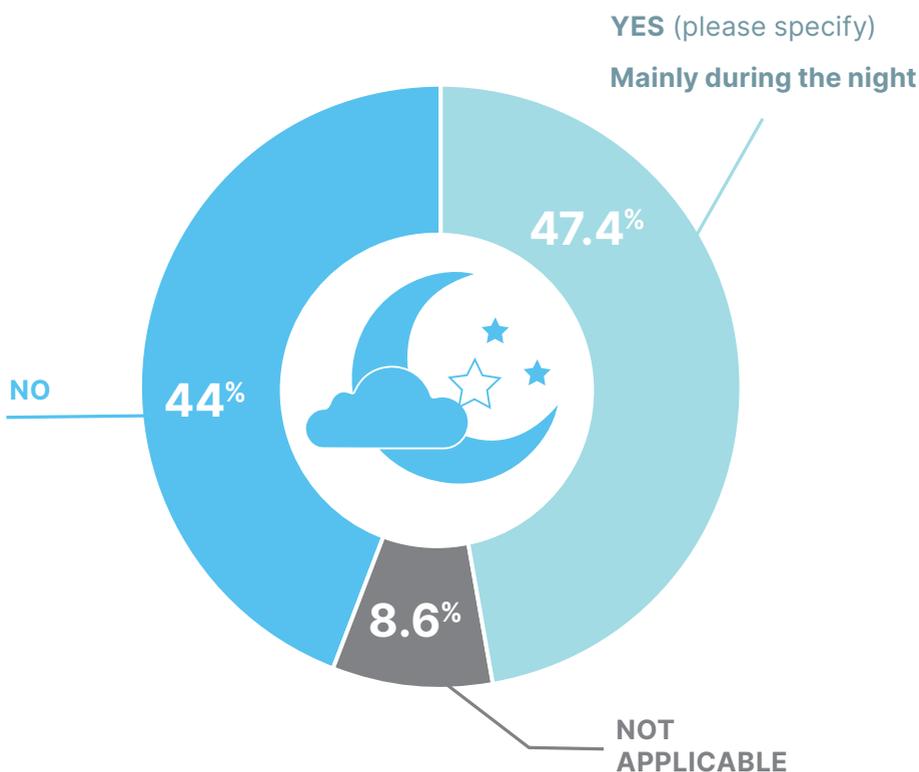


Question 16: How would you rate the impact of drooling on you/your family member/the person you care for regarding each of the following?

RESULTS

► **Nearly half of respondents report drooling worsening at specific times, mainly during the night**

Specific time when drooling is worse



Question 17: Is there a time of day when drooling is worse? If yes, when?

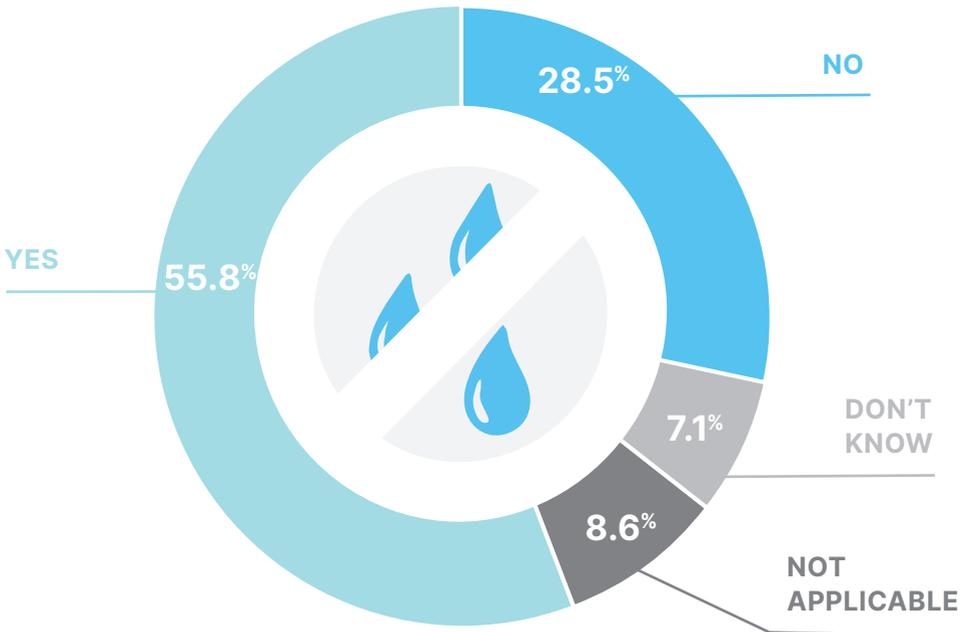
RESULTS

► Dry mouth is also frequently reported

- **56% of respondents** report that they have a dry mouth at times, despite – or because of – hypersalivation



Experiencing dry mouth

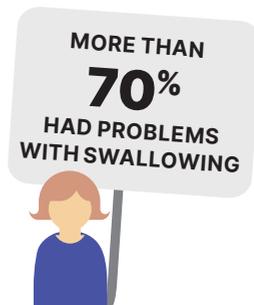


Question 18: Do you/your family member/the person you care for also experience a dry mouth at times?

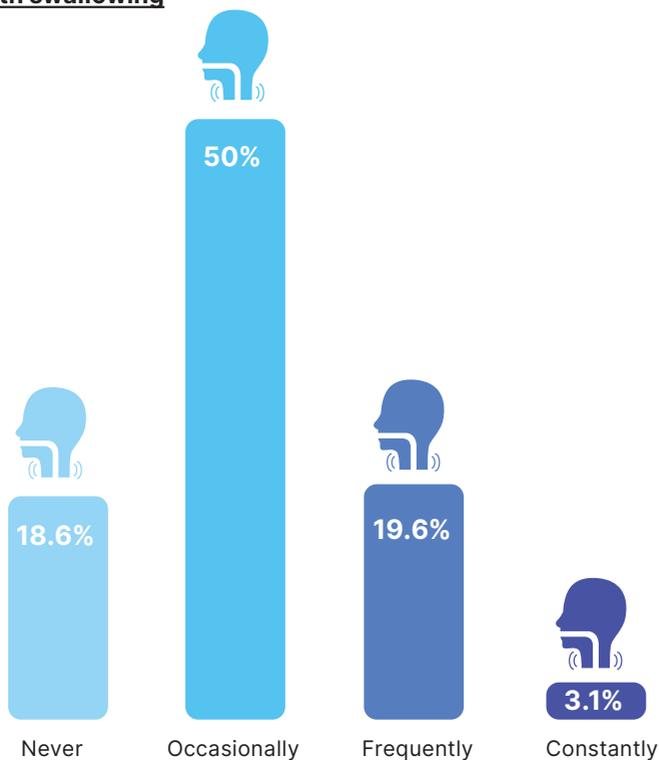
RESULTS

► Problems with swallowing

- **Half of respondents** occasionally have problems with swallowing
- Nearly **20%** experience frequent **swallowing problems** and **3% constantly** do so



Problems with swallowing



Question 19: Do you/your family member/the person you care for experience problems especially when swallowing food or drinks, eg coughing, gurgly voice or choking during or after eating or drinking?

RESULTS

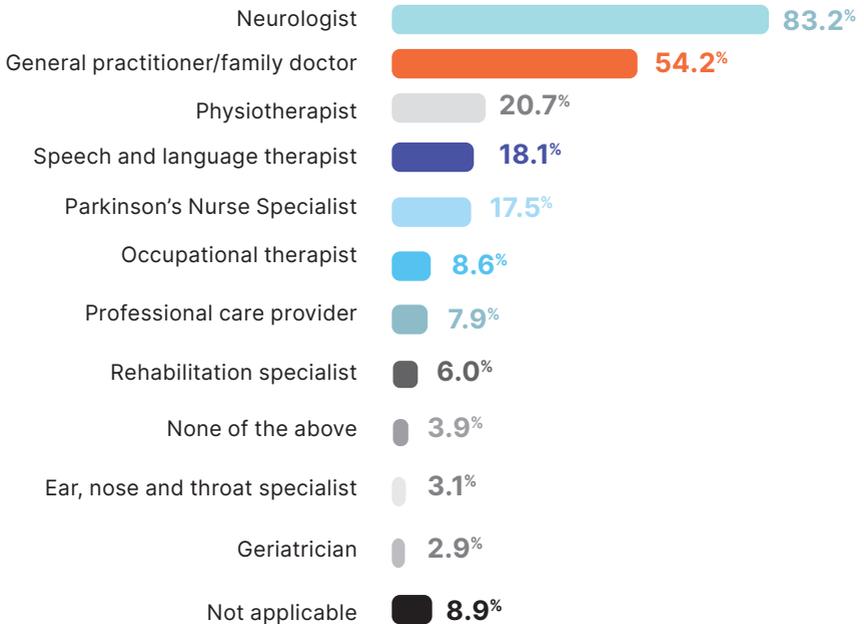
▶ Neurologists are the main contact

- For about **half of respondents**, the **family doctor is also involved** in treatment and care
- A **physiotherapist** is also involved in **just over 20%** of cases. A speech language therapist or (for UK only) **Parkinson's**

Nurse Specialist (PDNS) is involved in **less than 20%** of cases

- The geriatrician is the **least involved** HCP
- On average, **2.3 HCPs** are involved in care

Healthcare professionals involved in treatment



Question 20: Which of the following healthcare professionals are currently involved in the treatment and care of you/your family member/the person you care for?

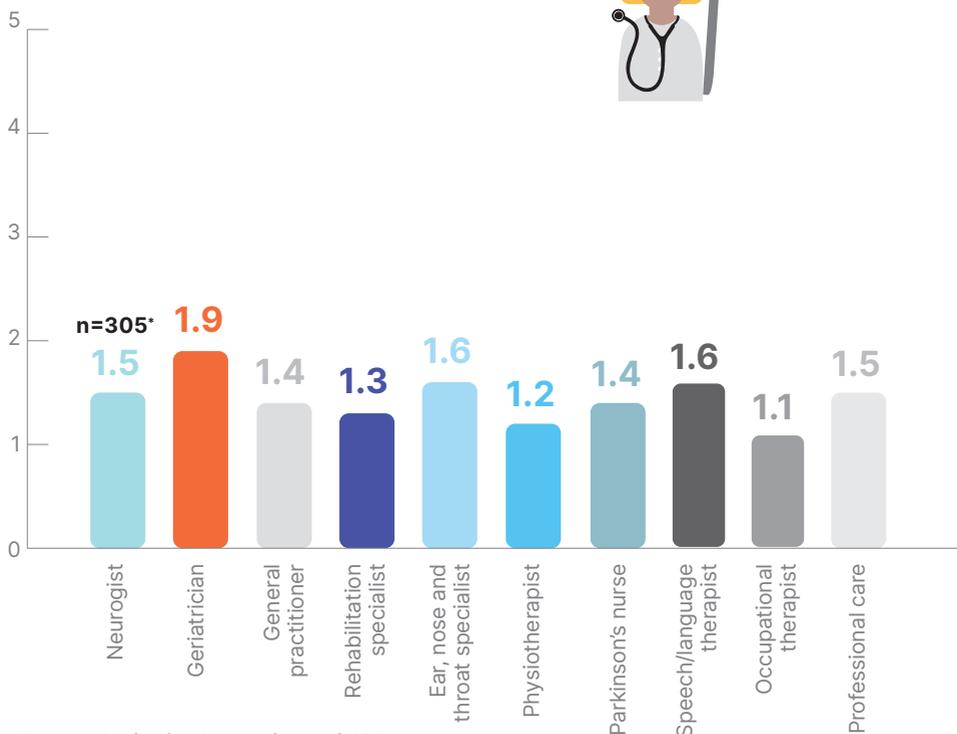
RESULTS

Overall low levels of attention from HCPs towards sialorrhea and its impact

- **Sialorrhea gets very low levels of attention from HCPs** – none beyond a 2 on a 5-point scale (where 1 equals does not pay attention/not interested at all and 5 would be pays attention/extremely interested)



Level of attention from HCP



*Smaller sample size for the remainder of HCPs

Question 21: Which of the following members of the care team pay attention to sialorrhea/drooling and to what extent do they acknowledge and address its impact? Please rate their interest in this symptom on a 5-point scale where 1 equals “does not pay attention/not interested at all” and 5 equals “pays attention/extremely interested”.

RECOMMENDATIONS



Research shows that sialorrhea has been found in up to 84% of people with Parkinson's (PwPs)*. It can be experienced in people at all stages of the condition and at all ages, yet the highest prevalence is found in the over 80s and those living with Parkinson's for more than 15 years.

This important survey has shown us how much of an impact sialorrhea can have on PwPs, not just on swallowing itself but also on quality of life and communication. It has also shown that a large percentage of people have not discussed this important symptom with their healthcare professionals – and have therefore not been given suitable advice about the possible treatment options available to them.

Saliva is produced by salivary glands, and about 1.5 litres is secreted each day. We would normally manage this level of secretion by swallowing approximately once per minute as a result of saliva accumulating in the mouth. We do this involuntarily and naturally both during the day and during the night, thanks to our swallow reflex.

PwPs often experience the feeling of excess saliva in their mouth or throat. Research has shown that this is mainly due to a reduced number of swallows per minute. What was once an involuntary movement now requires more voluntary thought. PwPs need to consciously execute that 'clearing swallow' to deal with their saliva.

Swallowing difficulties are common among PwPs, and sialorrhea has been found to be an indicator of just that – reduced swallow function and reduced swallow frequency. Excess saliva in PwPs can therefore lead to sialorrhea.

'This important survey has shown us how much of an impact sialorrhea can have on PwPs, not just on swallowing itself but also on quality of life and communication'

I would strongly recommend that anybody experiencing sialorrhea discusses their symptoms with a member of their multidisciplinary team, and requests a referral to a speech therapist as soon as possible, as they will be able to help with the sialorrhea as well as with any related swallowing difficulties.

I also urge you to read and digest the 'Tips and tricks' recommendations section on the next page. I have included a number of strategies designed to help people with Parkinson's manage their sialorrhea symptoms throughout the day. I hope you will find them useful.

Veronica Clark

Highly specialist adult speech and language therapist – UK
President, The Malta Parkinson's Disease Association
President, The European Parkinson's Disease Association (EPDA)

*Van Wamelen, D.J., Leta, V., Johnson, J. et al. Drooling in Parkinson's Disease: Prevalence and Progression from the Non-motor International Longitudinal Study. *Dysphagia* 35, 955–961 (2020). <https://doi.org/10.1007/s00455-020-10102-5>

TIPS AND TRICKS

Because the swallow reflex is not being triggered as often as it should – and you're therefore left with a feeling of excess saliva – we need to engage in strategies to help manage this throughout the day. Here are some options to try right away:



Ensure you are taking your **medications** on time to avoid any 'off' periods that could impact on your swallowing function



Swallow more often in the day – and swallow purposefully to clear that saliva. Try to tie this into a routine: for example, every time you receive a text message or an email (if this is something that happens very often). You could also use a 'swallow reminder app' (such as Swallow Prompt) to help you remember this



Keep your mouth super clean with **good oral care** twice a day – taking care to brush your teeth, gums and tongue with a soft toothbrush



Chew gum or suck a sugar-free sweet to promote more frequent swallows (only if safe to do so)



Clear excess saliva by **swallowing before talking**



Sip water often throughout the day – try keeping a bottle or glass close by. Every time you swallow water you will be clearing the saliva



Aim for an **upright body posture** and avoid tilting your head forward



Keep a **tissue** handy



Try to be aware of your **lips** – and keep them closed to stop saliva from pouring out of the mouth



Use a **barrier cream** on your lips if they become sore



Use a small **towel** on your pillow at night

Remember, a speech therapist can help you to implement this advice – and also assess other methods of treatment if required. You should know that there are treatments available for drooling that can improve your quality of life, and it is extremely important you know all the options available to you. This knowledge will help you make an informed decision on how to manage this symptom for you.



ACKNOWLEDGEMENTS

Thanks to the people with Parkinson's, their family members and carers who took part in this survey, and to the Parkinson's organisations from around the world who collaborated in the dissemination of the questionnaire:

EPDA member organisations

Davis Phinney Foundation

European Federation of Neurological Associations

European Patients' Forum

Oruen

Parkinality

Parkinson Canada

Parkinson Youngster

Párkinson! Y ahora qué?

PD Avengers

The Parkinson Alliance

touchNEUROLOGY

World Parkinson Coalition

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