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Understanding neck collar preferences and user experiences in motor neuron disease: A survey-based study

Samuel D.J. Spears^{a,d,*}, Yusuf F. Abdulle^{b,d}, Thomas Lester^a, Ryo Torii^c, Deepak M. Kalaskar^{a,**}, Nikhil Sharma^b

^a Division of Surgery and Interventional Sciences, University College London, London, NW32PF, United Kingdom

^b Department for Clinical and Movement Neuroscience, Queen Square Institute of Neurology, University College London, London, WC1E 6BT, United Kingdom

^c Department of Mechanical Engineering, University College of London, London, United Kingdom

^d National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG, United Kingdom

ABSTRACT

Background: Motor Neurone Disease (MND), is a debilitating neurodegenerative condition, which significantly impacts the quality of life of those affected. Neck weakness is one challenge faced by those living with MND and as such may require a neck collar to assist. However, the user experience and requirements related to these neck collars have not been comprehensively explored. Understanding these priorities is crucial for enhancing the well-being of MND patients.

Objective: To understand the priorities of people living with Motor Neurone Disease (MND) including user experience, requirements and the importance of neck collars used to aid neck weakness.

Methods: An online survey was used to investigate the perspectives and experiences of off the shelf neck collars used by people living with MND. The MND Association was selected as a strategic partner by their affiliations and access to large data base of MND patients.

Results: Survey highlighted a disparity between the actual duration MND patients wear their current neck collars and their desired duration, emphasising the need to integrate collars into daily activities. Key areas for improvement with existing neck collars centred on comfort and reduced restriction, with respondents expressing a preference for collars that offer support without impeding movement. Additionally, addressing pressure on the anterior neck region during collar use emerged as a critical requirement.

Conclusion: Current collars do not cause any clinical complications; however, they do fall short of meeting the expected needs of people living with MND, including discomfort, restricted movement, and pressure to the anterior region of the neck. This study highlights need to improve current collar designs to provide better quality of life for MND patients.

1. Introduction

Motor Neurone Disease (MND) is a neurodegenerative disorder that leads to the degradation of limb, respiratory and bulbar muscle strength.¹ People living with MND may develop neck weakness, resulting in a clinical syndrome known as ‘head drop’ or ‘dropped head syndrome.’ Dropped head syndrome (DHS) is described as a severe deformity in the kyphotic region or weakness in neck extensor muscles when both in the sitting or standing position.² As well as MND, other conditions can be associated with DHS can be considered neurodegenerative (MND, Parkinson’s, Multiple System Atrophy); neuromuscular (Myasthenia gravis, Lambert-Eaton myasthenic syndrome); Muscular (Polymyositis, Scleromyositis ... etc.); malignancy, and post-surgical² (for detailed breakdown of types of conditions associated with DHS (see **Supplementary data 1**). DHS contributes to problems with eating,

drinking, communicating, breathing, and swallowing.^{3,4} For people living with MND, neck collars are often prescribed to aid in the management of neck weakness.

Currently, patients are assessed as to whether they require head supports or collars by either an occupational therapist, physiotherapist, or an orthotist,⁵ usually in clinic as part of their standard care. Use of neck collars has long been established in pre-hospitalisation settings to treat trauma and are used to stabilize, manage, and brace the neck region to avoid further injury.⁶ As such, these collars have been assessed on how much they can limit cervical range of motion.⁷ They are also used to improve post-surgical outcomes by reducing pain, providing a sense of security, and aid in the management of neck weakness. Collars prescribed to people living with MND are primarily developed to restrict neck range of motion.⁶ This focus on restriction often leads to collars being rejected by people living with MND owing to discomfort.⁸ Also,

* Corresponding author. Division of Surgery and Interventional Sciences, University College London, London, NW32PF, United Kingdom.

** Corresponding author.

E-mail addresses: samuel.spears.20@ucl.ac.uk (S.D.J. Spears), d.kalaskar@ucl.ac.uk (D.M. Kalaskar).

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with prolonged use risks such as accelerated degradation of the muscle tissue, loss in vasomotor tone, skin breakdown, pressure sores and irritation may occur.^{9,10} Reed et al. reported that patients often reject collars because they are of limited use by people living with MND.⁸ However, there is little to no information documenting the experience people living with MND have when using their prescribed neck collar and how this compares to their needs.

This study aims to quantify the experiences of people living with MND with currently commercially available collars, to help identify the positives, negatives, and what is missing from the current 'off-the-shelf' neck collars. It will also identify desired use and requirements of collars by participants.

2. Methods

2.1. Survey development

A multi stakeholder group, representing clinicians, occupational therapists specialising in MND, engineers and an independent panel provided input on the online participant experience survey development (see Acknowledgements). The multi-dimensional survey assessed several factors: (1) previous experience with neck collars used to treat neck weakness; (2) current use of their collars compared with desired use; (3) areas of weakness/discomfort with current collars; (4) importance of factors affecting the design of the collar. The patient-reported survey was designed in-house, then coded, developed, and hosted on R. Grid, a clinical trial and research management system using their Electronic Data Capture module, an intelligent tool that allows accessible, auto-anonymised, real-time survey and data collection, evaluation and auto-reporting from participants, or carers of participants, on any device (see supplementary data 2).

The survey consisted of 18 questions split across 3 sections, evaluated by multiple-choice, image-choice, and scales-based (Likert Scale) answers, providing a straightforward 'checkbox' questionnaire for the ease of the participants. This survey was co-designed and optimised so that participants using Eyegaze technology could easily complete the survey without any additional burden. The first set of questions were used to understand participant experiences and the usage of their current collars in comparison with their perceived requirements. The second set was designed to understand participant preferences with collar measures (i.e., appearance, comfort, ease of use, etc.) and their experiences with collar fitting (e.g., how many they tried, how long for, areas of discomfort, etc.). Finally, the last section used a Likert rating scale ('strongly agree' to 'strongly disagree') to evaluate their current collar along with identifying their current collar.

2.2. Survey procedures

UCL's Research Ethics Committee (REC) approved the study protocol (study reference 20,583/001) wherein we used the online survey to obtain input from people living with MND regarding neck collars and their experience with them. All methods were performed in accordance with the relevant guidelines and regulations. All participants provided informed consent. The participant information sheet (PIS) described the need for participant input, the expected time to complete the survey (15 min), and what would happen to the results. It also assured survey participants that the survey is confidential and does not collect any personal data. We recruited participants by (1) working with the Motor Neurone Disease Association (MNDA) who hosted a page on their website with information regarding the survey opportunity and a link for targeted recruitment, (2) locally at National Hospital of Neurology and Neuroscience by the PI. Finally, (3) we posted the survey on social media whereby MND & ALS charities were invited to share the survey opportunity. The survey was opened from March 2, 2022 and data was collected on September 7, 2022.

3. Results

3.1. Experience and usage of current collars

A total of 38 people answered the survey, with 22 responses received in full. GraphPad Prism 9 was used to process data analysis. Questions 1–6 investigated the participant's current collar usage compared to their desired collar usage. Participants were asked the length of time they typically wear their collar, and then how long they thought they needed to wear a collar (Fig. 1). The survey shows that 45 % of participants currently wear a collar (Fig. 1A) whereas, 74 % stated that they felt they need one (Fig. 1B). For those who answered that they do not currently wear a collar, the survey prompted a follow up question to record their reasons: 51 % answered that it was because collars are "too uncomfortable", 44 % "too restricting", and 4 % responded "not necessary for me" (Fig. 1A). Finally, participants were asked which collar they currently use out of a list of well-established collars used in MND clinics. The most common collars are Headmaster and foam collars, both having 11 % of participants reporting use. However, 46 % of participants reported they did not use any of the collars listed (Table 1).

Participants were asked to tick activities they used their primary collar for, and then tick which activities they feel the need to use a collar for (Fig. 2) to identify any disparity between current collar usage and ideal usage. The largest disparity between current and ideal collar usage was for 'bathing/showering,' with zero participants reporting the use of their current collar. The second largest disparity was for 'Personal care' and 'In the Kitchen,' with only 27 % reporting using their current collar for either activity. Responses indicate that while current collars are being used for certain daily activities, participants are not using their current collars for as many activities as they would like to, which an ideal collar may allow.

3.2. Collar measures and experience

To identify the importance of different aspects of neck collars, participants were asked to rate their current collars in 5 different features (hygiene, comfort, ease of use, ease of putting on and off and appearance) (Fig. 3A). When asked about their current collar; 'Ease of putting On & Off' was reported as the best feature with an average answer of 3.5, whilst 'Appearance' was reported as the worst feature with an average of 1.19. After rating their current collar, participants then ranked the same features to determine which are the most important to them (Fig. 3B). The order from the most important to least important was comfort, appearance, hygiene, ease of use, and ease of putting on and off.

Next, participants were asked to identify any areas of discomfort (multiple choice) experienced when wearing their best fitting collar (Fig. 4). Results showed discomfort reported in all regions around the neck with the area of discomfort identified by the largest number of participants is "Front – Chin" with a 35 % response. The area of discomfort that the least number of respondents identified is on the "Right Side" 9 %.

3.3. Collar evaluation and identification

To evaluate participant interaction with their collars, a set of seven Likert-scale questions were designed (Table 2). Participants were asked to rate aspects of their collars on a scale of 1 (Strongly Disagree) to 7 (Strongly Agree). The most disagreed statement is "I am able to fit the collars on my own" whereas the most agreed statement is "No restriction to my natural breathing." Finally, participants were asked whether they think a well-fitting collar would be beneficial for them, with 96 % of respondents reporting "Yes" (Table 3).

4. Discussion

This survey aimed to understand and quantify the current usage,

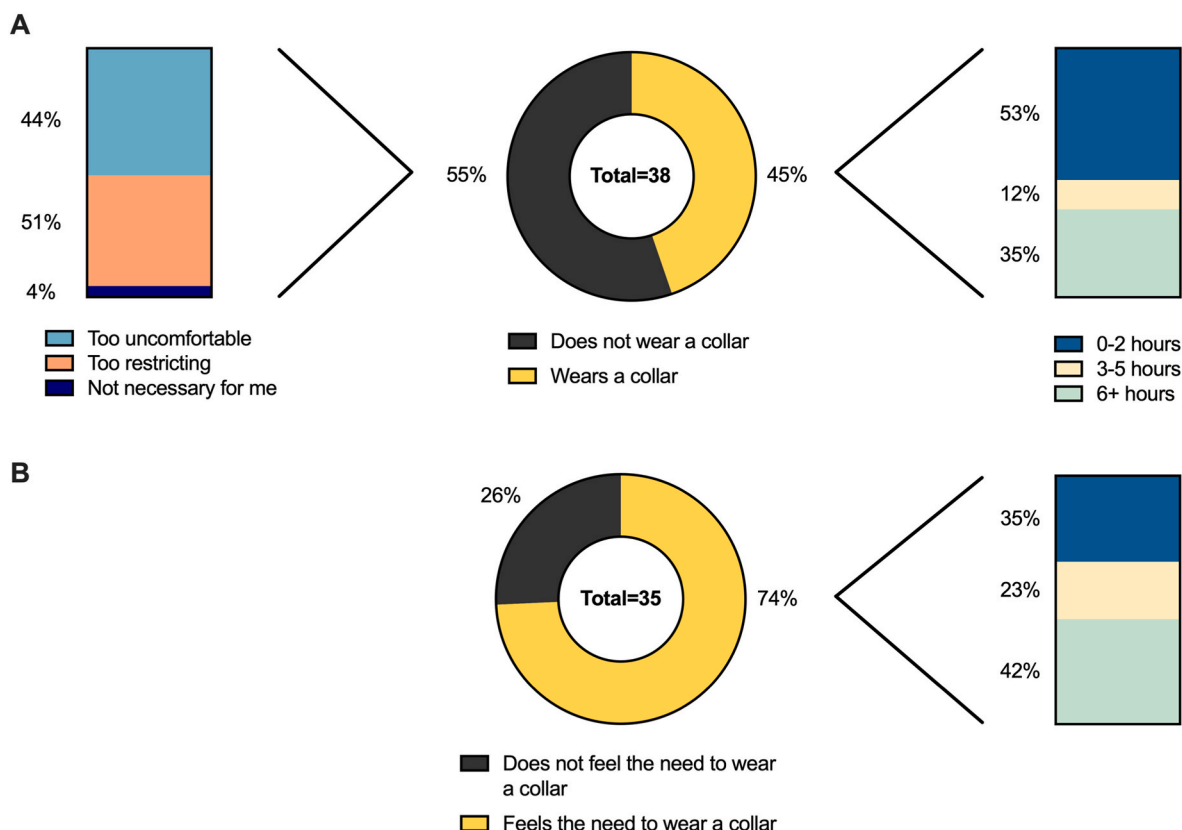


Fig. 1. Analysis of survey outcome on collar usage by MND patients (A) duration of use for ‘off-the-shelf’ collars (B) participant’s perception on how long they should wear a collar.

Table 1
Participant reported collars (n = 22).

Collar	Percentage of responses (%)	Type	Indication for use
Headmaster	11	Semi-Rigid	ALS, MS, Arthritis and DHS ¹¹
Miami J	6	Rigid	Trauma, Pre & Post Surgery ¹²
Foam Collar	11	Soft	Post-Trauma, Neck extension pain ¹³
Aspen Vista	0	Rigid	Trauma, Pre & Post Surgery, Musculoskeletal pain ¹⁴
StifNeck	0	Rigid	Cervical Immobilisation during transportation ¹⁵
HeadUp (Sheffield Snood)	9	Snood	ALS, Head Drop, Torticollis, Neck extensor muscular weakness and Conditions requiring neck support & improved alignment/control ¹⁶
Hereford	6	Soft	Trauma, MND, Torticollis, Cervical spondylosis, Rheumatoid arthritis ¹⁷
Ballert Oxford Collar	6	Rigid	Fatigue, C4 immobilisation ¹⁸
Philadelphia	0	Rigid	Post Trauma, RA/OA, Post surgery, Whiplash, Tracheotomy ¹⁹
Hensinger	3	Soft	Swallowing, Breathing & Good Eye Contact ²⁰
Semi-rigid Collar	0	Semi-Rigid	Spondylitis, Spondylosis, Rheumatoid arthritis, Osteoarthritis ²¹
Ortel C42 Cario	3	Rigid	Trauma, neck pain, spinal stenosis, cervical spondylosis, stabilization, compressive procedures, fracture management, cervical disc disease and radiculopathy ²²
None of these	46	N/A	-

compared with the desired usage, of neck collars used to alleviate neck weakness due to DHS for people living with MND. The results of this survey show a disparity between the length of time current collars are worn and the desired length of time to wear a collar, and a perceived need to use a neck collar more for daily activities. Comfort and restriction are highlighted as the main areas of improvement with current neck collars. This better understanding of patients’ experience and need will aid designing of a new collar specifically for people living with MND.

In the first section of the survey examining current use of neck collars compared with desired use, it was identified that lack of comfort and physical restriction are key reasons why people living with MND either do not wear a collar for the desired time or use one altogether (Figs. 1 and 2). When comparing the length of time participants currently wear their collar versus the length of time, they would like to wear one, the desired length of time was significantly more (Fig. 1).

Of these currently available collars, the Headmaster collar (semi-rigid) and Foam collar (soft) were reported as most used, followed by the HeadUp collar (snood) which was also reported highly. Both the Headmaster and HeadUp are designed to manage neck weakness in neurological pathologies, whereas the HeadUp is specifically designed for MND. Rigid collars, however, were the least reported with only 50 % of the rigid collars listed as being identified as used by any participant, whereas 80 % of the semi-rigid/soft collars were reported as being used. For soft/semi-rigid collars, the clinical indications for use have a wide application including ALS, neck pain, fatigue etc. For rigid collars, the common indications for use are trauma, pre and post-surgery and cervical immobilisation. This potentially indicates why people living with MND do not take up rigid collars as frequently, because the collars they need are to support the head, relieving head drop,⁶ rather than immobilising. The collar preferences reported in this present study differ from a study conducted by Sheehy et al. (2023) on neck weakness in individuals with MND. Sheehy et al. (2023) reported that the Soft Collar



Fig. 2. Analysis of participant response comparing which activities their current collar helps with vs which activities an ideal collar would help with? Question was multiple-choice, responses analysed by activity. Total participants for each question (n = 29).

(soft) and Aspen Vista (rigid) were the most popular collars, with the HeadUp not being used.²³ This compares with the current study where the Headmaster (semi-rigid) and Foam Collar (soft) were reported as the most popular; with the HeadUp (snood) also reported as used but with the Aspen Vista not used at all. It was reasoned by Sheehy et al. (2023) that both the Soft Collar and Aspen Vista were the cheapest options for soft and rigid collars respectively, and that these collars were easier to put on and take off by both patient, family member or carer, whereas the HeadUp was more difficult.²³ Sheehy et al. (2023) was conducted in Australia and so future work should aim to understand how clinic

location effects collar availability and choice.

It should be noted that in the UK collars are available at no extra cost to the patient via the NHS, so collar price does not factor in patient choice.⁵ Availability of collars may vary between NHS clinics, with clinicians supported to choose collars from an approved supplier list.^{24,25} If the patient requires a collar that is not available through their clinic, The Motor Neurone Disease Association (MNDA) can provide an equipment loan service.

People living with MND may experience different levels of collar-associated discomfort as levels of neck weakness vary individually due

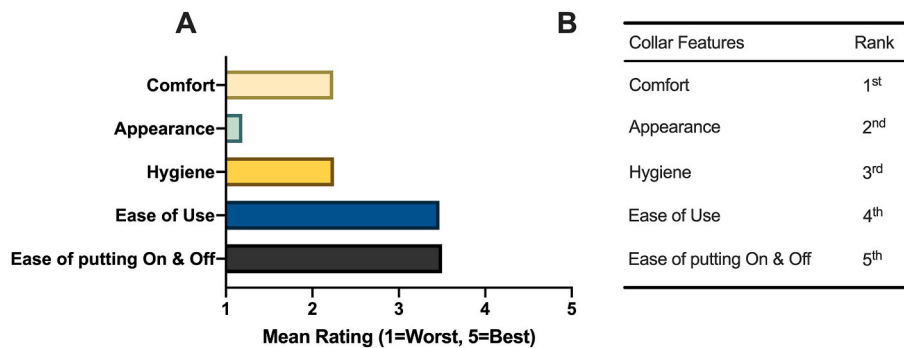


Fig. 3.

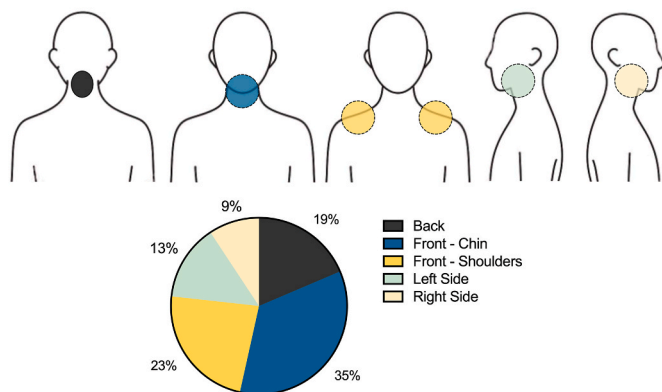


Fig. 4. Analysis of survey responses to “does your best-fit collar still have any areas of discomfort?” (Multiple Choice) (n = 23).

Table 2

Participant responses to rating their current collar.

	Current collar mean rating
No restriction to my natural breathing	n = 21 6.5
Supports my head effectively	n = 19 6.0
Allow me to move my head freely	n = 21 4.2
I can fit the collars on my own	n = 9 1.5
No additional difficulties eating when wearing the collar	n = 16 5.4
No additional problems drinking when wearing the collar	n = 16 5.5
The collar causes no restriction to my natural swallowing ability	n = 20 5.9

a. Rating derived from seven-point Likert scale: 1 = strongly disagree; 2 = disagree; 3 = disagree somewhat; 4 = neither agree nor disagree; 5 = agree somewhat; 6 = agree; 7 = strongly agree. n = No. of responses.

Table 3

Do you think a collar that is well fitting would be beneficial? (n = 23).

Options	Percentage responses (%)
Yes	96
No	4

to the difference in disease progression and manifestation.⁵ From other studies^{3,4,8,23,26–28} it has been observed that people living with MND rely on their collars in day-to-day life to combat the effects of head drop. For

those who rely on a collar heavily, due to the discomfort/restriction current collars are not able to be worn for prolonged periods of time. This was also reflected in Sheehy et al. (2023) study, which found that 50 % of participants were not able to wear their collar for as long as they needed. This was reported to be owing to a variety of reasons including discomfort, difficulty swallowing and the need to wear non-invasive ventilation masks.²³ Sheehy et al. (2023) found that of the collars reported, 42.3 % required some form of modification to improve comfort and/or ability to remove the collar. The relative ease of modifying a specific collar could be an influencing factor for collar choice within clinics.²³ The high proportion of collar modifications also highlights the current limitation of ‘off-the-shelf’ collars. The design of a new collar for people living with MND should factor in time to be worn, and more specifically prolonged usage. As indicated by the survey, there was a greater desire to wear a collar for 6+ hours compared with currently using a collar for 6+ hours.

Most participants indicated that they need to wear a collar for more activities than they do currently. Most notably, for bathing/showering which zero participants reported as an activity for which they currently use a collar. It is unclear from the survey why participants do not use their current collar for bathing/showering. The collars highlighted in this study all have some form of fabric/padding and range from being removable (i.e., Miami J) to fixed (i.e., Headmaster). People living with MND may not have multiple of the same type of collar, therefore wearing a collar with wet fabrics post bathing/showering may result in discomfort as it is recommended that these fabrics are allowed to air dry after being washed and the collar be removed to clean the neck area during cleaning & skin care (as stated in the manuals). However, as indicated in the survey, it is desired that a collar that can be used in a wet environment as well as be used in other areas of daily life. With the percentage of responses indicating a higher need for activities compared with their current collar, a new collar should be flexible in its design and allow for use in a variety of activities.

Comparing the participants’ ratings of features on their current collars with the ranking of importance of the same collar features, comfort was identified as the most important feature for wearers yet was also highlighted as one of the weaker areas in which current collars perform. Aesthetics was the lowest rated feature on participants’ current collars but was 2nd when ranked as important to them in a collar. It has been observed in clinic as a reason for not wearing a collar, as it can make wearers feel self-conscious when out in public with it drawing attention to them. This poses the biggest challenge when designing a new collar: being subtle enough that it does not draw attention or being too obvious, but also provide the support and requirements necessary for use. Current collars scored higher on ease of use and ease of putting on and off. Therefore, it is important to note when designing new collars aimed for people living with MND, comfort is a key area of improvement that should be focused.

The areas of discomfort reported by the most participants in current collars were the chin and shoulders at the anterior portion of the neck

region. These are key sites of mechanical interaction between user and collar when returning the head to its 'natural' position from a 'dropped' state. For a new collar looking to combat head drop for people living with MND, it is important that these sites are padded effectively to reduce a focal pressure. Sheehy et al. documented the direction of head drop, with 51.5 % reporting forward only, 42.4 % forward and to the side, and 6.1 % side only.²³ The direction of head drop was not assessed in the present study, but when examining the predominance of forward head drop reported by Sheehy (2023) suggests why the right and left side were the least reported areas of discomfort in this study, with 9 % and 13 % respectively. The question investigating discomfort was multiple choice, therefore the responses to side discomfort may be related to the head falling forward and to the side and not just side weakness. Not all head drops fall directly forward, but instead some fall only to the side, meaning correction to a neutral position may be easier, and result in less discomfort. Another factor not assessed in this study which can limit collar choice is muscle tone with collar stiffness, as individuals with lower muscle tone may require a more rigid collar to support excessive head drop, whilst high muscle tone may require a more flexible collar to accommodate the increased muscle stiffness. Further studies should aim to understand the implications of how muscle tone when present in head drop affects the support strategy used and if applicable the collars chosen. In evaluating specific measures for currently available collars, current collars were mostly perceived as positive i.e., no restriction to my natural breathing, with the only exception being ability to fit the collar on their own, something which has previously been identified.²⁶

This survey highlights the key requirements and expectations for collars used by people living with MND to alleviate DHS. Patient feedback highlight various design consideration including:

(a) improving comfort and appearance, (b) ability to be used in both wet and dry environments, (c) to meet needs of daily activities, (d) ability to be worn for long periods of time without causing discomfort, (e) limit restriction, (f) indicating focus on support rather than restriction of movement, (g) reduce pressure between the interaction of the collar, especially the anterior portion of the neck region.

However, DHS is not unique to MND. Therefore, other pathologies which use neck collars to correct head drop may benefit from investigating the needs/requirements from users compared with the feedback of current collars.

5. Limitations

This study has several limitations. The survey was designed for ease of completion as an online survey, rather than data captured online and in-person. Although the survey was designed for accessibility, it was limited by the predominant use of 'checkbox' and 'slide-to-rank' questions, to reduce the time burden for completing the survey, particularly for people using assistive technologies, such as Eyegaze technology. Additionally, the auto-anonymisation design specified that no identifiable information would be collected. While both helped to achieve inclusive, unbiased, and quick responses, it made it difficult to allow follow up questions to certain responses to elaborate. Further work should include branching logic in the surveys for elaboration on responses. They should also consider expanding survey collection both online and offline in clinics or elsewhere in person whereby, a professional or proxy could record participants' answers and allow for a section for them to complete with sufficient support. Finally, the severity of the participants neck weakness/head drop was not assessed which may influence the preferred support strategy used by the participant. To better understand support strategy used by people living with MND, further work should aim to understand the type of head support used with neck weakness progression.

6. Conclusion

Whilst current collars do not cause any negative clinical

implications, this survey highlighted that they do fall short of meeting the requirements of people living with MND. Respondents desire a collar that can be worn for longer periods and allow for use with more daily activities. The survey has helped illuminate key factors that can be used to assess collars in the future. Comfort was identified as the most important factor in a collar, with current collars falling short of attaining this. This study highlights a need for new collar design as off-the-shelf collar do not adequately address MND patients' daily needs.

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Data availability

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

CRediT authorship contribution statement

Samuel D.J. Spears: Conceptualization, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. **Yusuf F. Abdulle:** Conceptualization, Investigation, Writing – original draft. **Thomas Lester:** Writing – original draft, Writing – review & editing. **Ryo Torii:** Investigation, Methodology, Supervision, Validation, Writing – original draft, Writing – review & editing. **Deepak M. Kalaskar:** Conceptualization, Investigation, Methodology, Supervision, Validation, Writing – original draft, Writing – review & editing, Funding. **Nikhil Sharma:** Conceptualization, Formal analysis, Investigation, Methodology, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

Declaration of competing interest

NS is CEO & co-founder of BioCortex Ltd.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2024.101585>.

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