

Service Evaluation of Respiratory needs in people with Advanced Multiple Sclerosis

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Context:

The National Institute for Health and Care Excellence guidance (NICE 2022) recommends that respiratory function should be assessed in the annual comprehensive review of people with multiple sclerosis (MS). However, despite risk of respiratory death in MS being almost 12 times higher than the general population (Hirst et al 2008), there is limited evidence to guide assessment and management of the respiratory needs of people with MS (Dereli et al 2022).

Objective:

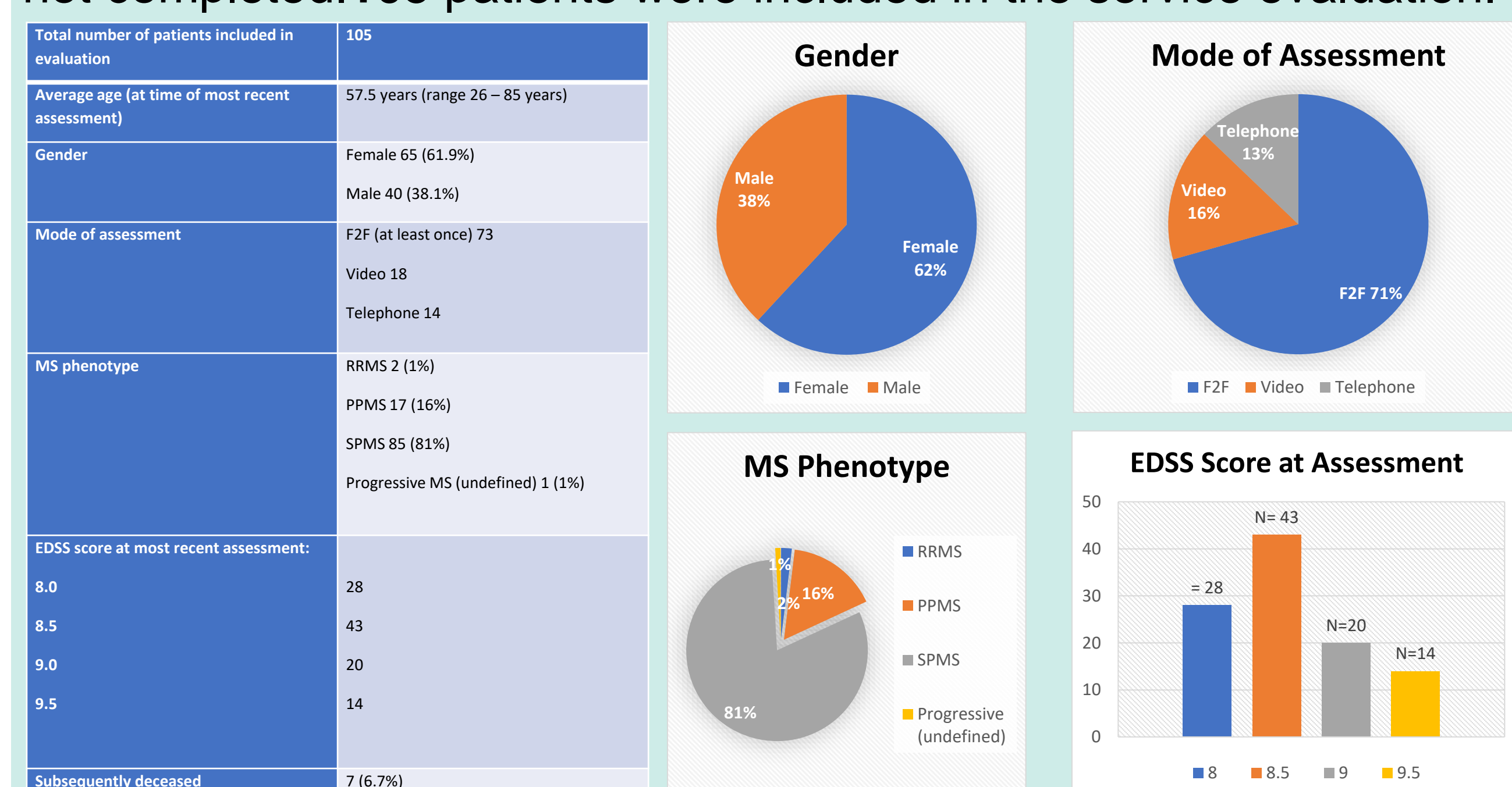
To understand the scope of respiratory needs of people with MS with advanced disability seen for an annual comprehensive review in a multidisciplinary team (MDT) clinic at a tertiary neuroscience centre.

Method:

A service evaluation was completed by reviewing the medical records of all patients with Expanded Disability Status Scale (EDSS) Score ≥ 8.0 reviewed in the MDT clinic from April 2021 to January 2024. Age, gender, disease phenotype, EDSS score, respiratory symptoms and suggested respiratory interventions were recorded. Dysphagia status in relation to respiratory dysfunction was also recorded.

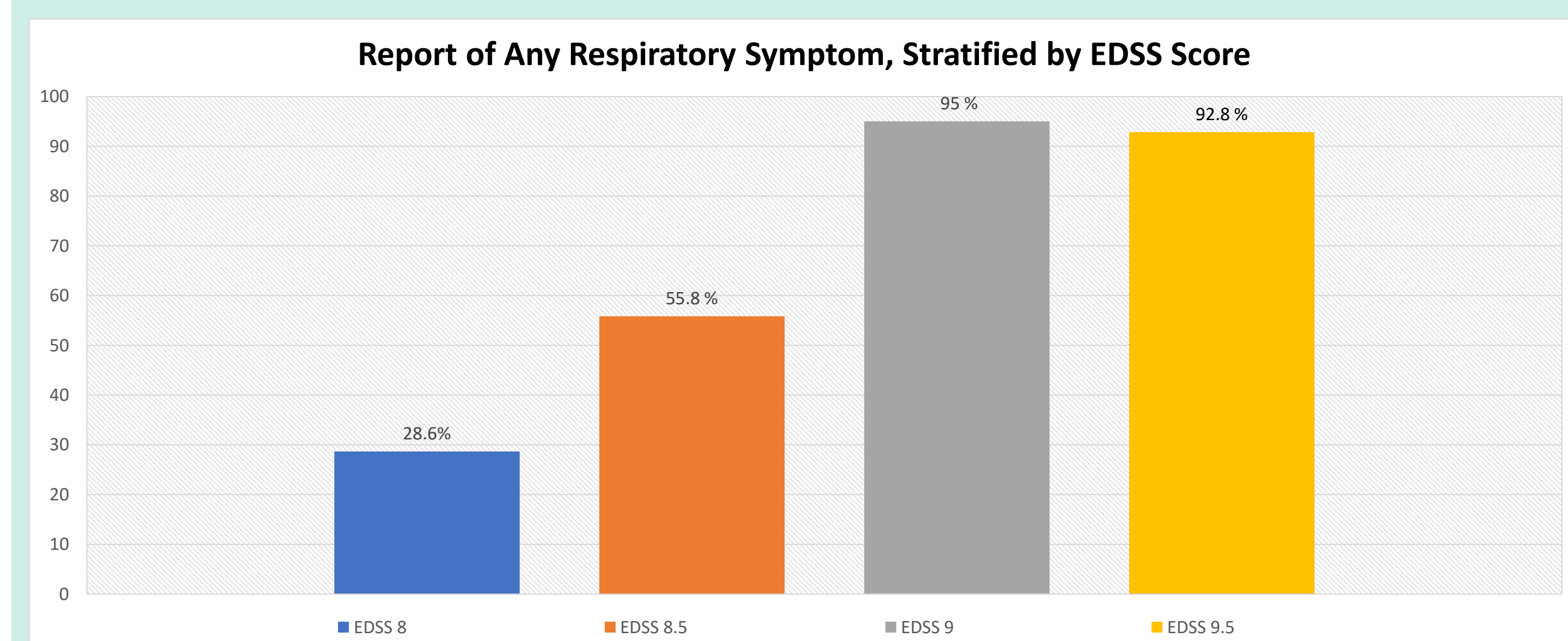
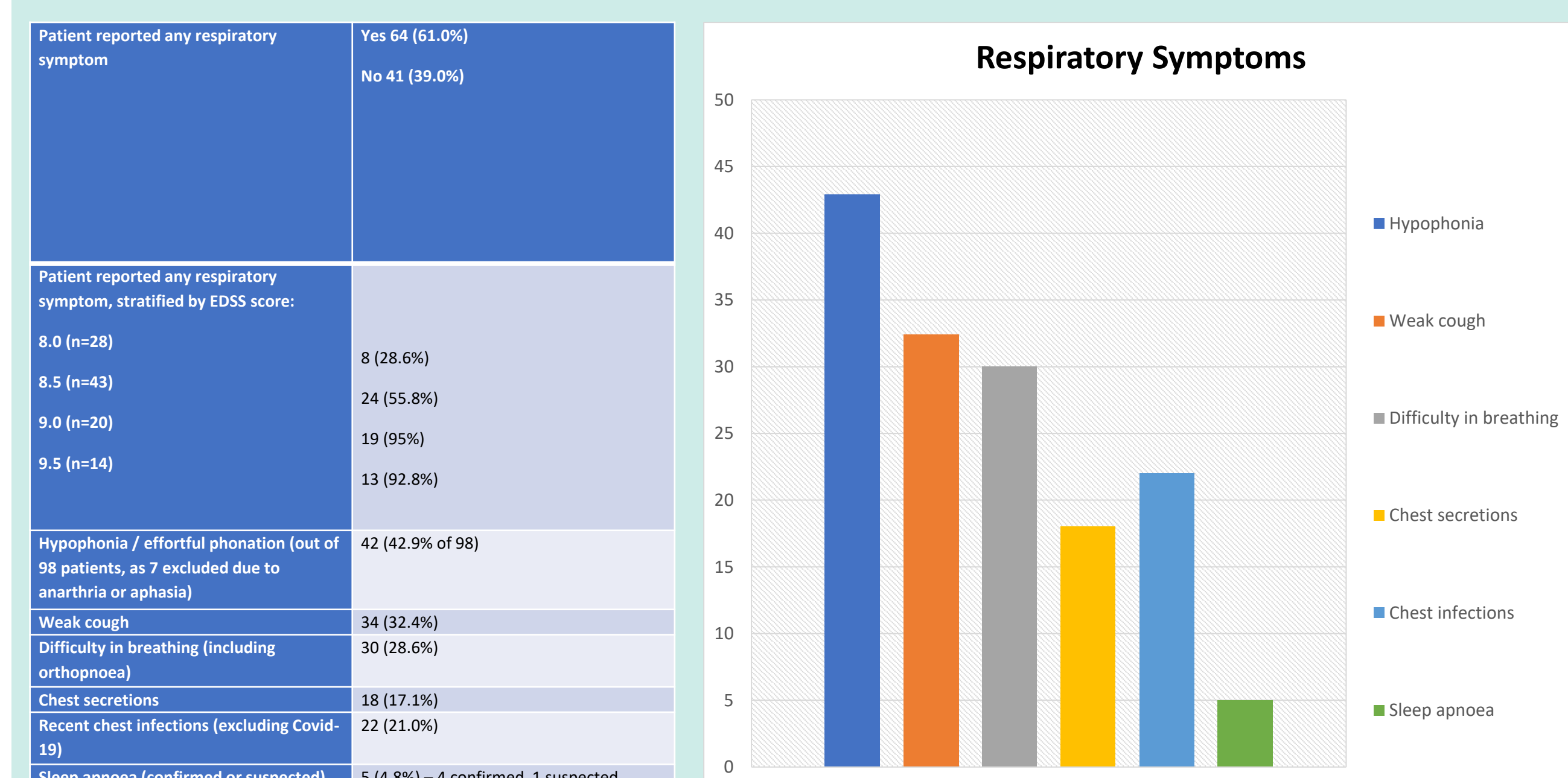
Results:

The medical records of 107 patients were reviewed. 2 patients were excluded, 1 the EDSS < 8.0 , and the other an initial assessment was not completed. **105** patients were included in the service evaluation.



Respiratory Symptoms:

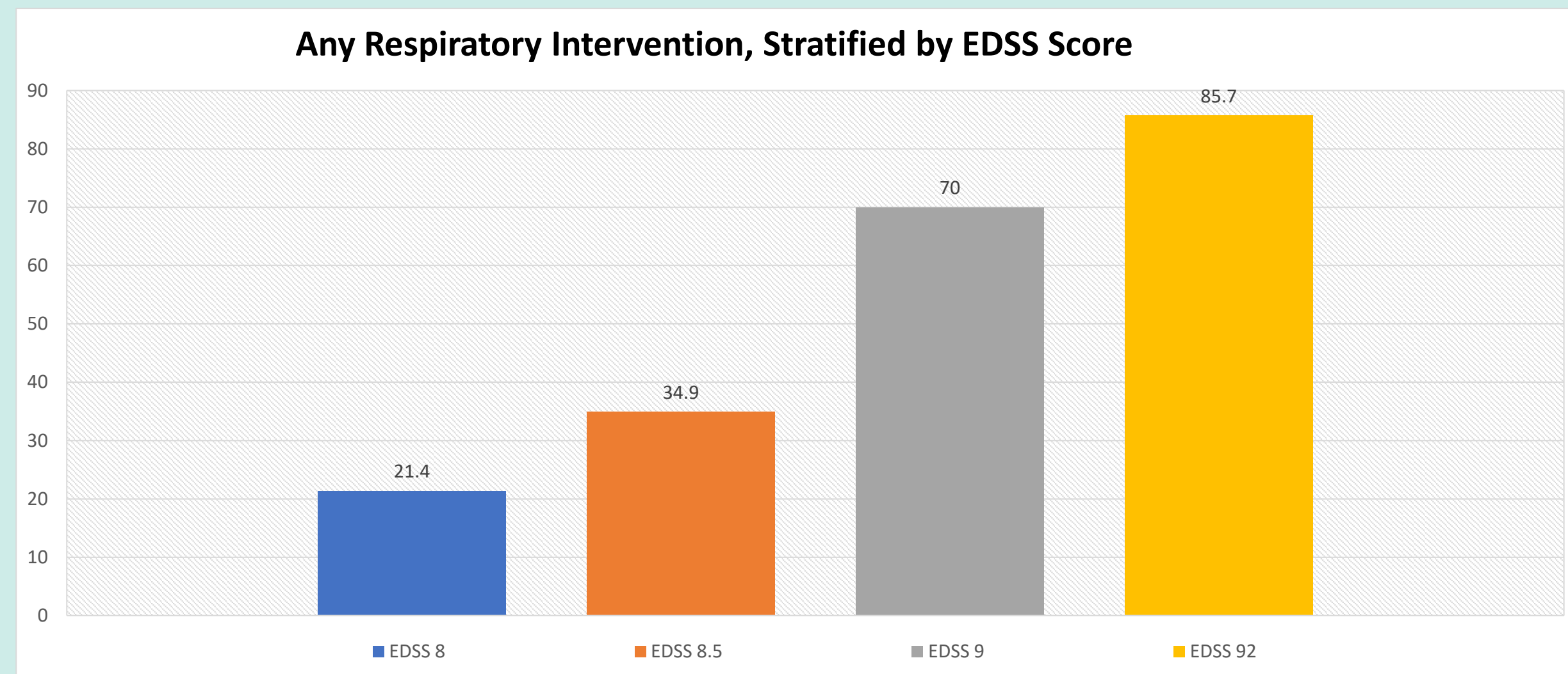
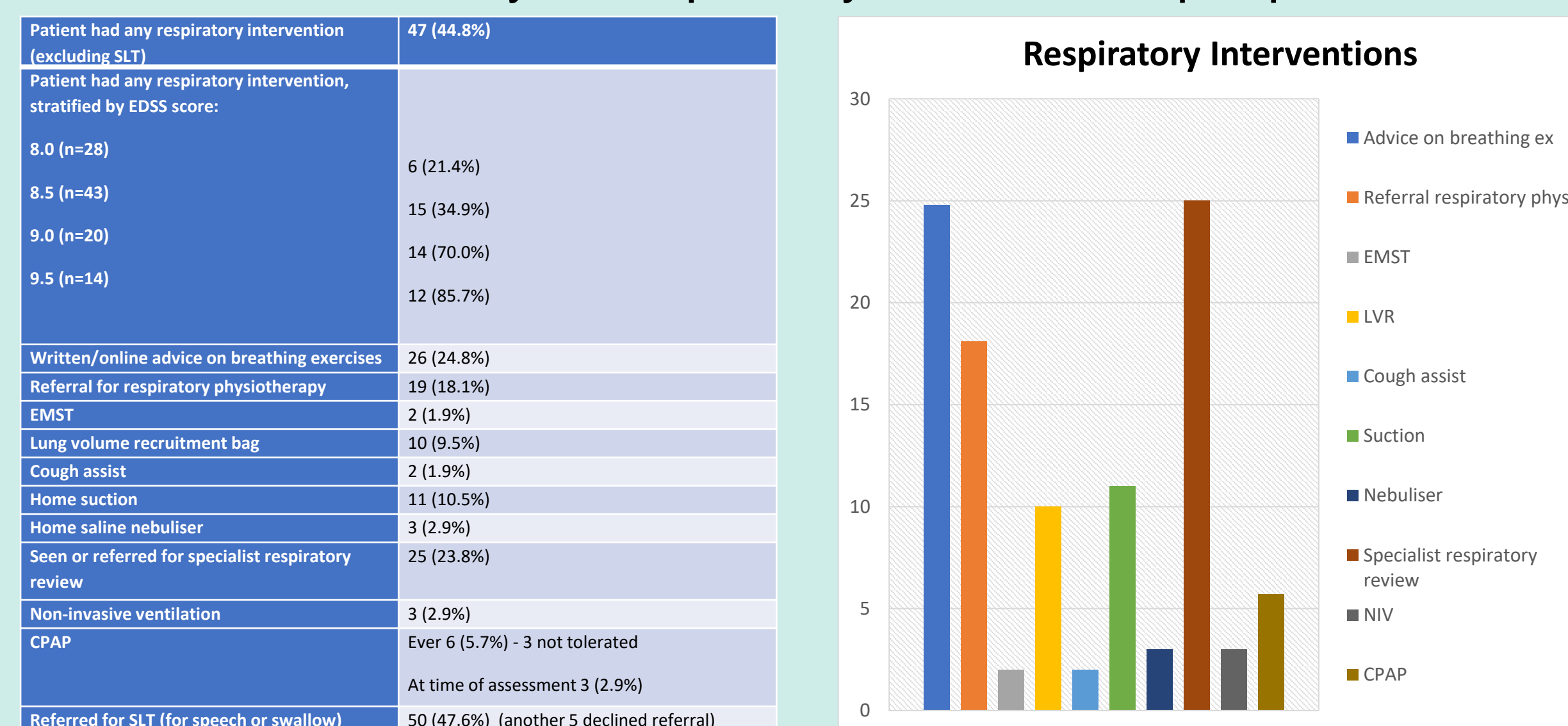
61% reported symptoms suggestive of respiratory dysfunction including hypophonia, weak cough, shortness of breath, orthopnoea, chest secretions, chest infections and sleep apnoea. Respiratory symptoms were more commonly reported with EDSS score ≥ 9 .



Respiratory interventions:

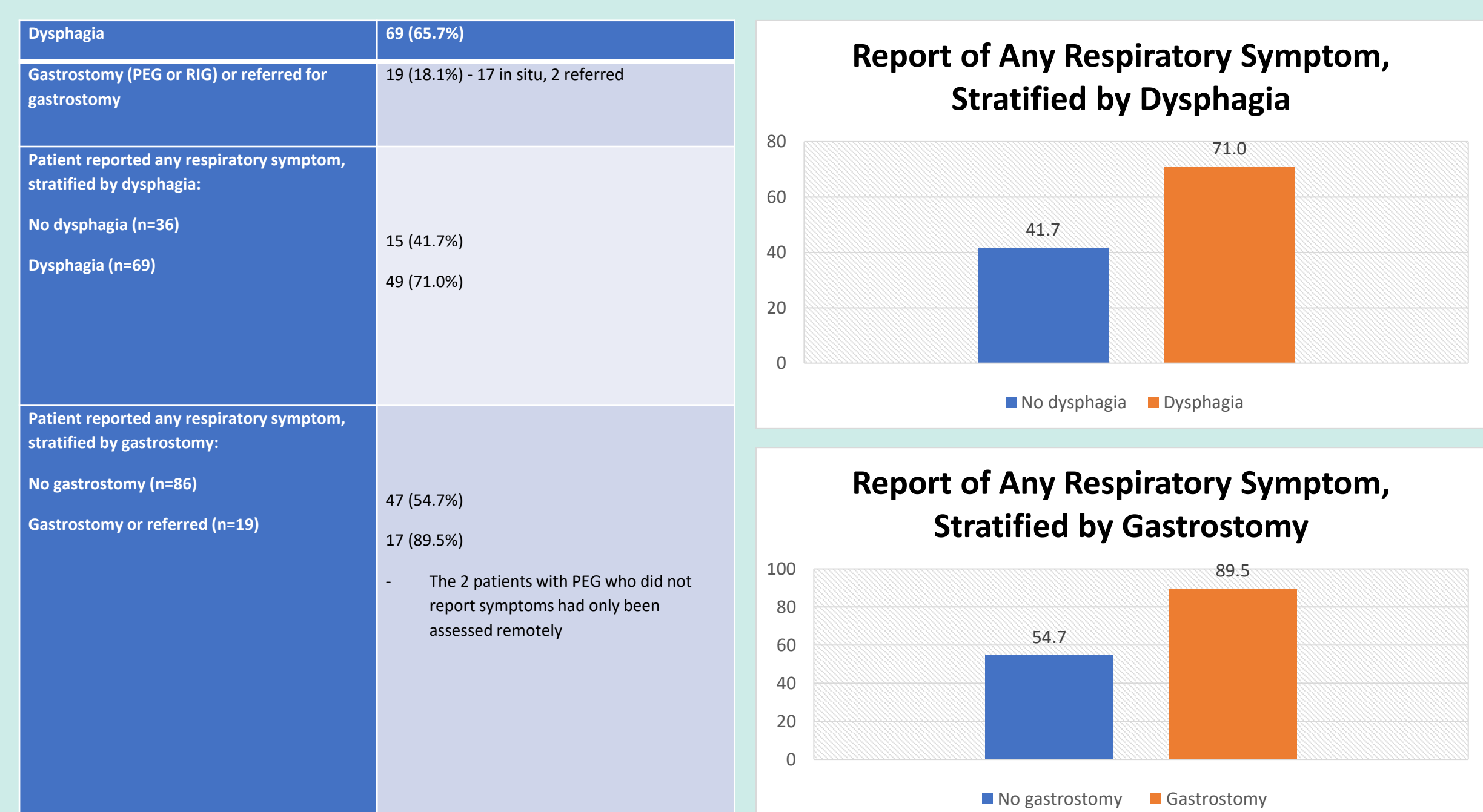
Recommended respiratory interventions included breathing exercises, respiratory physiotherapy or SLT (speech and language therapy) referrals for muscle strength training & cough augmentation techniques, and referrals to specialist respiratory clinics primarily for non-invasive ventilation assessment. **45%** of all patients received or were referred for respiratory interventions (excluding SLT referrals). Interventions increased with advancing EDSS score. Referrals to SLT (for either speech and swallow) were made for 48% of patients.

Referral and delivery of interventions was constrained by inconsistent availability of respiratory services for people with MS.



Dysphagia/ Gastrostomy:

65.7% of people reported dysphagia. **71%** of people with dysphagia reported respiratory symptoms, compared with **41.7%** of those without dysphagia. **18.1%** of people had a gastrostomy or were on a waiting list for gastrostomy. **89.5%** of people with or awaiting a gastrostomy reported respiratory symptoms, compared with **54.7%** of those without a gastrostomy.



Prognosis:

Sadly, 8 patients subsequently died within the service evaluation timeframe, highlighting the vulnerability of this patient group.

Conclusion:

This evaluation highlights that respiratory dysfunction is common in advanced disability due to MS. Respiratory symptoms and intervention need increased with advancing disability, and almost all people with EDSS score ≥ 9 reported respiratory symptoms. Respiratory interventions were frequently recommended, but referral and delivery was constrained by a lack of respiratory services and pathways for people with MS. Research is urgently needed into the respiratory needs of people with advanced MS and effective interventions.

References

- Multiple sclerosis in adults: management. NICE guideline [NG220] Published: 22 June 2022
- Dereli et al 2022 A Narrative Review of Respiratory Impairment, Assessment, and Rehabilitation in Multiple Sclerosis. 2022 Dubai Med J 0200;5:78-88
- Hirst et al 2008 Survival and cause of death in Multiple Sclerosis: a prospective population-based study. J Neurol Neurosurgery and Psychiatry. 2008 Sep; 79 (9): 1016-21